End of Life Decision Making in a Children's Hospital

Ethical and Practice Implications

Lesley D. Henley

University of Cape Town

2001

DECLARATION

I, Lesley Henley, declare this dissertation embodies only my original work, except where acknowledgement indicates otherwise, and that no part of it has been, or is being submitted for a degree at this or any other University.

I empower the University of Cape Town to reproduce for research purposes either the whole or any portion of the contents of the dissertation.

Signed:

Signed by candidate

TABLE of CONTENTS

Abstract

Aims
To evaluate end of life practices among hospitalised children who died of HIV/AIDS.

Design
Retrospective chart review.

Setting
A public, secondary and tertiary children's teaching hospital in a developing country.

Patients
A consecutive series of in-patient deaths among HIV-infected children.

Main Outcome Measures
Identification of patients as dying, presence of do not resuscitate (DNR) orders, documentation of comfort care plans, whether end of life decisions were discussed with parents or caretakers, nature of diagnostic and therapeutic interventions in the last 24 hours of life, and presence of pain and distress in the last 48 hours of life.

Results
165 out of 167 in-patient deaths were reviewed. 79% of patients died in the general wards. The median age of patients was 4 months. The median length of hospitalisation was 6 days. 30% of patients fell in Category B. Patients with shorter lengths of stay were more likely to fall in Category B (median 4 days versus 7 days, P=0.0000). About 1 quarter of patients had a median length of stay of 25 days. 84% of patients had a DNR order, with a median of 4 days between admission and documentation of the order. DNR orders appeared simultaneously in only 41% of medical and nursing entries. 39% and 63% respectively of doctors did not document their justification for the DNR order or whether it had been discussed with parents. 50% of patients were identified as dying. Terminology such as 'TLC' and 'keep comfortable' designated 44% of patients to receive comfort care only. The median time between admission and identifying a patient as dying and documenting a comfort plan was 5 days and 7 days respectively. In 44% of folders there was no indication of whether the comfort plan had been discussed with parents. 73% and 62% respectively of patients with comfort plans received IV fluids and IV antibiotics in their last 24 hours of life. 55% of patients who died in general wards experienced pain and distress in the last 48 hours of life. Respiratory symptomatology and oral and oesophageal candidiasis accounted for most discomfort. 2 in 5 patients with a comfort plan failed to receive analgesia, despite pain and distress.

Conclusions
Despite extreme diagnostic and prognostic uncertainty, doctors made key end of life decisions. Doctors' practices often failed to meet procedural and ethical requirements in professional guidelines. Failure to discuss DNR orders or comfort plans with parents ignores their role as principal decision makers for their children. The low rate of comfort plans, compared to DNR orders, suggests doctors had difficulty making the transition from curative to palliative care. Many comfort plans were incoherent and included interventions neither meant for, nor likely to promote patients' comfort. Whilst fear of hastening death may explain doctors' reluctance to prescribe adequate analgesia, undertreating pain and distress in a dying child is of more concern morally and medically than the risk of suppressing respiratory effort. To achieve better end of life care for HIV-infected children, it will be necessary to improve practice patterns. A structured medical treatment plan that focuses on goals of care is proposed to manage transitions from life-sustaining treatment to palliation.

Abbreviations

AAP	Academy of Pediatrics
AIDS	acquired immune deficiency syndrome
CCP	comfort care plan
DNR	do not resuscitate
HBO_2	headbox oxygen
HIV	human immunodeficiency virus
ICU	intensive care unit
IPPV	intermittent positive pressure ventilation
IV	intravenous
LP	lumbar puncture
N-G	nasogastric
NPO_2	nasal prong
PCP	*Pneumocystis carinii* pneumonia
PICU	paediatric intensive care unit
RCPCH	Royal College of Paediatrics and Child Health
RXH	Red Cross War Memorial Children's Hospital
SCCM	Society of Critical Care Medicine
TB	tuberculosis
TLC	tender loving care
TPN	total parenteral nutrition

Definitions

End of Life Decisions

An end of life decision was defined as documentation in the patient's folder of at least one of the following:

- a do not resuscitate order
- identification (i.e. evidence) of the patient as dying
- a comfort care plan
- other restriction orders to withhold or withdraw specific interventions

No end of life decision was defined by the absence of a specific order to limit interventions.

Evidence of Dying

Language in the folder such as 'end stage', 'dying', 'situation hopeless', 'prognosis poor', 'terminal' was interpreted as evidence of dying.

Do Not Resuscitate (DNR) Order

DNR orders were defined as explicit orders to limit the use of cardiopulmonary resuscitation (CPR) in the event of cardiac arrest and/or mechanical ventilation in the event of respiratory arrest. Orders restricting admission to the paediatric intensive care unit were interpreted as decisions to withhold ventilation since this intervention only takes place in the intensive care setting in Red Cross Children's Hospital (RXH). DNR orders in RXH are typically abbreviated as 'Not for CPR' ('not for cardiopulmonary resuscitation') or 'Not for IPPV' ('not for intermittent positive pressure ventilation').

Comfort Care Plan

A comfort care plan was defined by notations such as 'palliative care only', 'TLC', 'supportive care measures only'.

Withholding Treatment

Withholding treatment was defined as the considered decision not to institute a medically appropriate and potentially beneficial intervention.

Withdrawal of Treatment

Withdrawal of treatment was defined as discontinuation of active interventions already in use.

Pain and Distress

Pain and distress was broadly defined as:

- behavioural distress such as 'crying+++', 'very miserable baby', 'very irritable'
- descriptive reports of pain and distress such as 'mouth very sore', 'working very hard', 'buttocks excoriated', 'penile ulceration'
- symptomatology that suggested pain or discomfort such as, 'recessing+++,' 'distressed+++', 'distended+++', 'oral thrush+++'.

LIST of TABLES

List of Appendices

Acknowledgements

I wish to thank:

Terry Fleischer	Bioethics Centre, Groote Schuur Hospital for supervisory and intellectual support
Dr Tony Westwood	Department of Paediatrics and Child Health, University of Cape Town for technical and medical support
Records Department	Red Cross Children's Hospital for provision of medical folders

Chapter 1: Introduction, Aims and Methodology

1.1 Introduction

Improvement of care at the end of life has been the focus of intense investigation,[1] critical commentary,[2-3] and commissioned articles[4,5] in prestigious medical journals to raise professional awareness of the subject. Rapid expansion of web sites dedicated to end of life care extends accessibility of information well beyond specialist medical and nursing journals, and is further testimony to worldwide interest. This interest has evolved from the recognition that while we have the capacity to sustain patients through many life-threatening illnesses, we will at times be unsuccessful, and if it is no longer possible to prolong life we must provide compassionate care in the face of death. Despite the substantial literature addressing the care of dying patients, serious problems still exist in the medical care of children at the end of life. Many children suffer significant pain and other distressing symptoms,[6-8] continue to receive aggressive care in intensive care units (ICUs) until the last few days of life,[8,9] and lack continuity in their care.[10]

Interest in end of life care for children is not new. Medical experts have written about doctors' responsibility to gravely ill children,[11,12] ethicists have proposed guidelines for treatment at the end of life,[13-17] and medical councils, professional associations and working committees have published recommendations for care of critically and terminally ill infants and children.[18-23] Difficulties in developing policies for withholding and withdrawing life-sustaining treatment, that need to accommodate different moral viewpoints and meet specific legal requirements, are also described.[24] In addition, empirical studies spanning continents have explored doctors' practices regarding limitation of life-sustaining treatment in neonates[25-26] and children.[27-35] Studies have also surveyed doctors' attitudes towards the termination of life-saving care.[36-38] Yet noticeably missing from this considerable literature is information on end of life care for children with HIV/AIDS. Except for limited research[6] and commentary on pain management,[39] little is known about the process of end of life decision making in children with terminal HIV/AIDS, a uniformly lethal disease in the developed and developing world.

Furthermore, scant attention has been paid in the paediatric literature to subsequent management of patients once a decision to forgo life-sustaining care has been made. Many issues need to be addressed if humane care is to be given to these children until they die. For example, which treatments should be discontinued? Should all life-prolonging treatment be stopped simultaneously? If not, in what order should treatments be withdrawn? What is the rationale at work in the withdrawal of treatment and what are the goals of care in these situations? According to data from adult studies, doctors prefer to withdraw or withhold life support in sequence, or forgo some forms of life support while retaining others.[40-41] Rarely is all life support withdrawn simultaneously. Evidence also shows doctors withdraw treatment they perceive as expensive, scarce or artificial.[42] In general, for example, physicians prefer to withdraw blood products and prefer not to withdraw intravenous fluids. Moreover, doctors choose to withdraw forms of therapy supporting organs that failed for natural rather than iatrogenic reasons, recently instituted rather than longstanding interventions, and therapies that result in immediate death. On the other hand, they may continue therapies that delay death in the face of diagnostic uncertainty.[43] Likewise, health care professionals in a paediatric intensive care unit prefer to limit invasive interventions such as cardiopulmonary resuscitation and haemodialysis compared with less invasive care such as antibiotics.[44] Collectively, these findings signify that once decisions to limit life-sustaining therapies are taken, the actual process reflects other moral, social and clinical goals which though satisfying clinicians' own

perceptions of what is right or wrong, may interfere with achievement of what for the patient is arguably the ultimate goal: a peaceful, dignified death. That said, recent policies to provide palliative care for children with life-threatening or terminal conditions, and the growing body of evidence to underpin better pain and symptom control are noteworthy developments.[45-48]

Yet, with one exception,[33] published data depict end of life practices for children in developed countries. In South Africa (SA) research evidence is limited to one study, which describes the process of withdrawing and withholding care among adult patients in an ICU.[49] There are no similar data for children who die in hospital, although one attitudinal survey in a teaching hospital revealed marked value differences between doctors and nurses and mothers towards withdrawal of ventilation in hypothetical scenarios of severely compromised infants.[50] Certainly, findings from a survey in 1997 of randomly selected professional nurses in a local children's hospital are cause for concern.[51] Two in five respondents indicated they had recently nursed a child they felt had suffered unnecessarily in hospital. A further 9 out of 10 nurses felt parents were ill informed when signing consent for medical interventions. Unsurprisingly, 98% of respondents believed the children's hospital needed an ethics committee.

In short, not enough is known about end of life practices relating to limitation of life-sustaining treatment or relief of suffering to assess whether doctors adopt a systematic and compassionate approach to the care of dying children. Arguably, to provide exemplary end of life care a doctor must first decide a child is dying, then he should provide medical care appropriate for a terminally ill child. Crucially, improving terminal care for hospitalised children depends on clinicians' ability to recognise that patients are dying, and their readiness to limit aggressive treatment and plan comprehensive palliative care. Generally this requires a shift in goals from cure or prolonging life to a primary concern for comfort. Ideally this should prompt a complete reassessment of a patient's care, from diagnostic evaluations and medications, to discontinuing treatment that does not contribute to the new goals, particularly where the burden of such interventions outweighs their benefits. Yet, according to the evidence, many children are denied a peaceful and dignified death owing to prolonged aggressive life-sustaining treatment, with inadequate attention to relief of pain and suffering.

However, given universally low patient:staffing ratios in public hospitals in developing countries, any attempts to raise the quality of end of life care that rely exclusively on improvement of individual doctor-patient decision making may be misguided. In this regard the final comments of the principal investigators in the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) intervention are instructive.[52] Based on the wholesale failure of this costly intervention that aimed to improve end of life decision making, Lynn and co-workers believe improvement in end of life care will only be achieved through system level innovation, and quality improvement in routine practice patterns. Indeed, these investigators now reject the basic assumption on which SUPPORT was based: that the course of care for seriously ill hospitalised patients is the result of individual, patient-level decision making that could be improved with better counseling and information. Instead, they consider the course of care is more likely to be shaped by how the system of care is organised. In light of these findings, this study investigated end of life decision making among HIV-infected children with a view to identifying areas of practice requiring bedside and institutional level reform.

1.2 Aims

The evaluation of current end of life practices is a necessary first step to improve the quality of care of children dying in hospital. Indeed increased medical accountability for the quality of end of life care demands rigorous examination of underanalysed areas of practice. Evidence from well-resourced countries highlights gaps in end of life care for children. For terminally ill children with HIV/AIDS, shortfalls in knowledge regarding end of life practices are even more substantial. There are no published data on end of life care for children who die in public hospitals in SA. Data on end of life decision making among children with HIV/AIDS are necessary because HIV/AIDS accounts for an escalating proportion of hospital admissions and hospital deaths in SA. To this end, this study aimed to investigate end of life decision making among children with HIV/AIDS who died in one children's hospital. The findings are intended to assist the development of clinically and ethically appropriate policies for comprehensive and compassionate medical and nursing care for dying children. In turn, such improvements may go some way towards surmounting the sense of hopelessness among health professionals dealing with overwhelming numbers of dying patients in a context of diminishing resources and limited treatment options.

1.2.1 Objectives

More specifically, the study aimed to determine:

1. The proportion of patients identified as dying.
2. The proportion of patients with documented Do Not Resuscitate (DNR) orders and other care restrictions.
3. Any documented rationale for the DNR order.
4. The provision of comfort care plans.
5. Whether DNR orders or comfort care plans were discussed with parents or caretakers.
6. The extent and nature of diagnostic and therapeutic interventions *in the last 24 hours* of life.
7. The presence of pain and suffering *in the last 48 hours of life.*
8. Associations between end of life decisions and clinically relevant variables such as age, severity and length of stay.

1.3 Methodology

1.3.1 Design

A chart review of a consecutive series of in-patient deaths was performed to examine end of life decision making during patients' terminal hospitalisation.

1.3.2 Setting

The study was undertaken in Red Cross War Memorial Children's Hospital (RXH), a public, secondary and tertiary teaching hospital providing comprehensive medical care to an ethnically diverse, predominantly low-income population. Rotating registrars and senior house officers under consultant supervision provide most medical and surgical services. Limited multidisciplinary services including physiotherapy, occupational therapy and social work are provided.

1.3.3 Sample

The sample included all patients who died from HIV/AIDS-related causes between February 1998 and June 2000 in RXH. The study sample was drawn from a computerised register of deaths at RXH. The confidential register, instituted in February 1998 by a paediatric consultant, contains the folder number, age at death and certified cause(s) of death of all children who die at the hospital or whose death at home is certified by a RXH doctor. Two hundred and eleven children died from HIV-related causes between February 1998 and June 2000. To meet the study's objectives, only patients who died in the in-patient medical and surgical, general and intensive care wards were included. Patients were excluded if they died at home or in the hospital's emergency services (Table 1). One hundred and sixty seven patients were eligible for inclusion. However, given an under-certification rate of 11.4% (95% confidence interval 6-17%) for HIV-related deaths, this figure may underestimate the actual number of deaths caused by HIV/AIDS at the hospital.[53]

Table: 1
Sample Selection

		N
Sample Population		**211**
Exclusionary criteria:		
Died at home		22
Died in the emergency out-patient service		10
Died in the emergency out-patient ward		8
No documentation of death in the folder		2
Died at a Day Hospital		1
PCR negative at post mortem		1
	Subtotal	**44**
Inclusionary criterion:		
Died in in-patient wards		**167**

1.3.4 Data Collection

A structured questionnaire (Appendix 1) was used to collect data from patients' medical and nursing records, medicine charts and death summaries. Although most data extraction was limited to the terminal hospitalisation, occasionally it was necessary to review previous admissions for evidence of prior DNR orders or decisions to withhold invasive investigations and life-sustaining treatment. Data collected included the following areas:

- Sociodemographic and clinical characteristics of patients
- Place of death
- PICU admissions and deaths
- Resuscitation
- DNR orders or any other orders limiting care
- Evidence of dying
- Evidence of a comfort care plan
- Length of time between admission to end of life decisions and from decision points to death
- Social work intervention
- Morphine administration
- Diagnostic and therapeutic interventions *in last 24 hours* of life
- Evidence of pain and distress *in last 48 hours* of life

For purposes of this study, end of life decisions include identification (i.e. evidence) of patients as dying, issuing a DNR order, recommendations for a comfort care plan and decisions to withdraw or withhold life-sustaining interventions. Assessment of whether a clinician considered a patient to be dying was determined by language in the medical notes such as "end stage", "dying", "situation hopeless", "prognosis grim", "moribund" and the like.[54] Reference to patients as being critically ill was not considered evidence of dying. DNR orders were defined as explicit orders to limit the use of cardiopulmonary resuscitation (CPR) in the event of cardiac arrest and/ or mechanical ventilation in the event of respiratory arrest (Not for IPPV – not for intermittent positive pressure ventilation). Orders restricting admission to the paediatric intensive care unit were interpreted as decisions to withhold ventilation since this intervention only takes place in the intensive care setting in this hospital. Data on DNR orders were transcribed verbatim in order to evaluate their clarity and scope. Statements in the medical notes such as "no heroic measures" were considered too imprecise to constitute a DNR order, although the frequency of such statements was noted. Documentation of orders to limit other life-prolonging measures, "no blood transfusions", for example, was also recorded verbatim as evidence of intent to withhold life-prolonging treatment. Withdrawal of treatment was defined as discontinuation of active interventions already in use, for example, extubation and removal from the ventilator. Evidence of a comfort care plan was based on notations such as "comfort care only", "supportive measures only" and "palliative care only". Information on resuscitation was cross-referenced with a manual record of "red box" use, kept by a nursing sister in charge of the central sterilisation service at the hospital. Equipment needed for resuscitation is kept in red boxes. Nursing sisters, following use of a red box for CPR, complete forms that are returned to the central sterilisation service. These forms provide an accurate record of actual episodes of CPR in the hospital.

A pilot study of 10 records from general wards and the PICU of patients who had died of HIV/AIDS revealed the most frequent diagnostic and therapeutic interventions during hospitalisation. With the exception of routine nursing care (weighing and mouth care, for example) and micronutrient supplementation, all common interventions were itemised in the questionnaire to facilitate data collection. Less frequent interventions, such as a CT scan to confirm a brain death, were recorded in an open-ended format. A specific intervention was counted only once. For example, if 1 or more nebulisations was administered in the last 24 hours of life, the treatment was counted only once for that patient. The presence of pain and distress in a patient's last 24 hours was determined by phrases in doctors' and nurses' notes such as "distressed +++". "patient very miserable", "crying+++" or "very irritable". Social work visits were noted if there was a direct entry by these services in the medical record or a mention of their intervention by another discipline.

A paediatric consultant independently reviewed 12 randomly selected, completed questionnaires to evaluate content validity and reliability of data collection. Consensus regarding interpretation of evidence of dying and comfort care plans was reached through discussion. Agreement between the researcher and reviewer on other areas was high, although interrater reliability was not statistically assessed. The consultant also offered practical guidance about the location of selected information in medical records. The same consultant determined disease severity (A–mild, B–moderate, C–severe)[55] for 102 (62%) patients. In the remainder, the researcher classified patients as falling into Category C based on documented use of this classification in patients' notes or reference to patients as having terminal or end-stage AIDS. The classification system is based on signs and symptoms or diagnoses related to HIV infection.[56] In this system, infected children are assigned to one of four mutually exclusive clinical categories: Stage N, no signs or symptoms; Stage A, mild signs

or symptoms; Stage B, moderate signs or symptoms; or Stage C, severe AIDS-defining signs or symptoms. Although most children pass from Stage N to A, B and C in that order, others may pass directly from N to B or N to C. Examples of conditions in Category A include recurrent or persistent upper respiratory infection or otitis media and dermatitis. Examples of conditions in Category B include anaemia, single episodes of bacterial meningitis, pneumonia or sepsis, recurrent or chronic diarrhoea, persistent (>2 months) oropharyngeal candidiasis (thrush) in a child >6 months and lymphocytic interstitial pneumonia. Examples of conditions in Category C include multiple or recurrent serious bacterial infections (septicaemia, pneumonia, meningitis, abscess of an internal organ), oesophageal or pulmonary candidiasis, *pneumocysitis carinii* pneumonia and wasting syndrome in the absence of a concurrent illness other than HIV infection. Categorisation according to immunological status is not routinely undertaken at RXH.

1.4 Analysis

Quantitative data were summarised and analysed on a personal computer using Epi Info Version 6. Qualitative data, such as verbatim pain reports and verbatim comfort care plans, were categorised according to themes and counted. Key independent variables, in particular, age and length of stay, were analysed as categorical and continuous variables. For example, to better understand practice patterns, the sample was divided into quartiles according to length of stay, each consisting of approximately 40 patients. In contrast, age groupings (0-6 months, 7-12 months, 13-24 months, 25+ months) were based on local findings that HIV-infected children below 6 months of age at time of diagnosis have a higher risk of death than older children (odds ratio of 4.7 and median survival of 2 months).[57] Accordingly, age groupings were unevenly skewed towards younger groupings. Analyses that treated age and length of stay as continuous variables offered valuable additional information that may have been lost due to rigid categorisation of these variables.

Frequency and percentage distributions, single and multiple cross tabulations, and Kruskall-Wallis one-way analysis of variance were the most commonly used statistical analyses. Mantel Haenszel chi-square, Fisher's Exact Test (when expected values were less then 5) and Kruskall-Wallis chi square equivalent were used respectively to test the statistical significance of associations between categorical variables and differences between means for ordinal data. A probability level of less than 0.05 was used to establish statistical significance. In general, probability levels are reported in the main text when they reflect statistically significant results. Non-significant P-values are tabulated in appendices. P-values for analyses involving very low cell counts are not reported since the analyses are considered too unreliable. Most percentages are rounded to the nearest number.

With the exception of frequency counts, disease severity Category A was excluded from analyses because only 1 patient in this study fell in this category.

1.5 Ethical Considerations

Neither patients' nor doctors' identifying details were extracted from medical records. Therefore, parental consent was not necessary for the study. Permission to undertake the study was obtained from the Chief Medical Superintendent of RXH, the Head of the Department of Paediatrics and Child Health and the Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town.

1.6 Overview

In the following chapter, policies and consensus statements of professional associations as well as empirical data relating to end of life decision making in children are reviewed. The literature review includes a synopsis of research findings related to withdrawing and withholding treatment in neonates and children. Whilst most published data relate to care restrictions in intensive care settings, several studies examine end of life decision making in hospital generally and among children with chronic diseases specifically. The review includes policies, practices and attitudes relating to pain management in children. Included in the review is a limited ethical analysis of important distinctions that influence medical decision making. Examples include perceived distinctions between withholding and withdrawing medical care, extraordinary and ordinary care, artificial hydration and nutrition, and the doctrine of double effect. Analysis and discussion of empirical data from this study are presented respectively in Chapters 3 and 4. Finally in Chapter 5 recommendations are offered to improve end of life care of hospitalised HIV-infected children.

Chapter 2: Literature Review

2.1 Introduction

A report from the United Kingdom[58] suggests 12 principles necessary for a good death, important among which is knowing when death is coming and understanding what to expect, retaining a measure of control over what is happening, being afforded dignity and privacy, adequate pain relief and symptom control, access to spiritual and emotional support, and crucially, being able to leave when it is time to go, by not having life pointlessly prolonged. Fulfilling the promise of a good death or, put differently, improving care at the end of life, is the focus of intense international study. In SA, where paediatric HIV/AIDS accounts for between one half and one quarter of all ward deaths in some teaching hospitals, the need to examine whether children experience a good death is compelling.

Published policies and recommended ethical guidelines on end of life care for children provide the starting point for this literature review. These are followed by a review of empirical studies of end of life practices in acute hospital settings. Despite the best societal intentions, research shows children continue to receive aggressive care at the end of life with inadequate attention to pain and symptom control. These studies remind us that for many children a good death remains more a hope than standard medical practice. Recent policy developments to address palliation and pain relief are examined, followed by a review of ethical issues and doctors' attitudes to pain management. Finally, reports of perceived educational needs and initiatives to improve skills of persons caring for terminally ill children are briefly examined.

2.2 Policies on Forgoing Life-sustaining Treatment in Infants and Children

In the past decade, task forces of medical and ethical experts have developed guidelines to assist clinical decision making in situations where technological advances enable prolongation of life even in circumstances where there is no reasonable hope for recovery to a functional or interactive existence. In the early stages consensus statements focused mainly on end of life decision making among adult patients but more recently prestigious bodies such as the American Academy of Pediatrics (AAP) [18-20] and The Royal College of Paediatrics and Child Health (RCPCH)[21] have issued authoritative position papers on aspects of end of life care for children. Likewise, paediatric subspecialties have published position statements on, among others, children in persistent vegetative state[17] and children with cancer.[23] Based on critical analysis of available evidence on end of life care, these policies provide practical ethical and legal guidance respectively to clinicians and the courts and legislatures on end of life matters. Important features of these policies, in particular the locus of decision making and the ethics of withdrawal and withholding life-sustaining medical treatment, are examined.

Policies developed in the USA are examined first, followed by frameworks produced in the UK and Europe. In general a chronological approach is used. In 1990[18] and 1995[19] respectively the AAP published guidelines on forgoing life-sustaining medical treatment in children and high-risk newborns. The AAP noted that limiting or stopping life support is appropriate if treatment serves only to preserve biological existence or if the overall goal of therapy has shifted towards the maintenance of comfort. Recognising no intrinsic moral difference between categories of treatment, the AAP defined life-sustaining medical treatment as encompassing all interventions that may prolong children's lives. Thus life-sustaining medical treatment includes both dramatic interventions such as mechanical ventilators and kidney dialysis machines and less technically demanding measures such as antibiotics, chemotherapy, and artificial nutrition and hydration.

The AAP[18] sees no legal or ethical distinction between initiating or discontinuing a treatment, although it recognises that reluctance to stopping therapy may prevent clinicians beginning treatments that may help some patients, particularly in the face of uncertainty. The AAP recognises that starting a therapy is often necessary to adequately evaluate a patient's condition. Any treatment derives its medical justification from the benefits that the parents (and patients) and clinician hope to achieve by employing it. When the treatment has achieved those benefits or can no longer be expected to do so, it loses its justification and may be withdrawn. Indeed, according to the AAP, continuing nonbeneficial treatments may harm patients and may therefore constitute a legal as well as moral wrong.

The AAP[18] accords parents the primary authority to make decisions regarding life-sustaining treatments for their children. This assumption is based on the fact that most parents have a deep love and commitment to their children's welfare and that parents will have to deal with the consequences of whatever decisions are made. In making decisions for children who are incompetent the AAP recognises, in descending order of preference, 3 standards of decision making. First, the subjective standard relies on explicit statements made by the child before decisional capacity was lost. Second, if there is no clear evidence of what the child would have wanted, then the parent should apply the substituted judgement standard. This requires parents to apply the child's own values, religious beliefs, and preferences in arriving at a treatment decision. If this information is not available, or more commonly, if the child never attained the capacity to espouse such preferences, then the third option is the best interest standard. The best interest standard involves weighing the benefits and burdens of life-sustaining medical treatment. The benefits may include prolonging life on the understanding that continuation of biological existence without consciousness may not be a benefit, or improved quality of life following the institution of treatment, which includes reduction of pain. The burdens of life-sustaining medical treatment may include intractable pain, emotional suffering, invasive or inhumane interventions or any other activities that severely detract from the patient's quality of life. Whilst the AAP stresses that 'quality of life' must be assessed in terms of the patient's perceptions, not those of the parents or health care providers, practically speaking this is not possible in infants and young children who have never been able to formulate a value system. It is noteworthy that the AAP rejects attempts to equate quality of life with the notion of social worth as judged by others. In short, the best interests of a child are usually presumed to be life preserving but in the face of irreversible illness this presumption requires careful exploration. Best interests may require a plan of care that focuses on the child's need for comfort and symptom relief, rather than the provision of life saving medical therapy, to ease the process of dying in a way that promotes the comfort and dignity of the child.

If, in the physician's opinion, treatment no longer confers benefit and should be forgone, then the patient and parent should be informed. Patients and parents may not compel a physician to provide any treatment, which in the professional's judgement is unlikely to benefit the patient. In case of disputes between a patient or parent and the physician, the AAP recommends the parties seek consultative help from professionals skilled in behavioural assessment and counselling, an ethics committee, religious advisors if appropriate, and as a last resort, the courts.

Finally, the AAP[18] recommends explicit documentation in a patient's medical notes of any order to forgo life-sustaining treatment. Such an order should include information on the diagnosis, prognosis, patient or parent's wishes, the content of discussions with involved parties, any

disagreements or unresolved issues, and the recommendations of the health care team. Patients with no specified limits on therapy will receive all medically appropriate interventions including cardiopulmonary resuscitation. The AAP's recommendation that 1 physician be designated as the spokesperson for the health care team to discuss progress and treatment options with the family is a worthwhile addition to their 1995 position paper[19] on forgoing life saving treatment for newborns. Appointment of a named key worker would facilitate communication between patients and parents and the health care team.

In 1996,[20] in response to increasing debate in clinical and public circles about the high costs in terms of money, time and psychosocial consequences, of neonatal and paediatric intensive care, the AAP issued a further policy statement that specifically addressed the ethical use of advanced medical technology (ventilatory support for example). In line with earlier statements, the AAP confirmed the primacy of patients' and parents' values as the basis for decisions. The statement noted that prognostication is an inexact science the results of which cannot tell clinicians which particular patient will live or die and with what residual problems. In this light the AAP underscored the need for individualised decision making for newborns, infants and children requiring advanced medical technology. Significantly in its rejection of bedside rationing the AAP went beyond previous policy statements. Whilst acknowledging that limited resources require equitable limits on medical treatment, the AAP stressed that resource allocation decisions about which children should receive intensive care resources should be made explicitly at a public policy level, not at the bedside.

Subsequently in 1999, the AAP and the Pediatric Section of the Society for Critical Care Medicine[59] jointly published a set of flexible guidelines for developing admission and discharge policies for paediatric intensive care units (PICUs). Although the AAP promoted the use of sound physiological criteria (wherever possible) as the basis of policies, the statement recognised the absence of benefit to the patient and futility as acceptable criteria for discontinuation of intensive care. The AAP recommended that hospitals adapt these guidelines to develop institutionally appropriate policies. The AAP noted that the absence of clear guidelines could result in substantially inconsistent decisions in similar kinds of cases. By adopting a comprehensive set of guidelines institutions could reduce the possibility of inconsistent decisions.

In turn, the Society for Critical Care Medicine (SCCM)[60] published a carefully researched statement detailing a principled and procedural approach to provision of treatments deemed futile or inadvisable. To this end, the SCCM classified interventions into 4 categories: treatments that have no beneficial physiological effect, treatments that are extremely unlikely to be beneficial, treatments that have a beneficial effect but are extremely costly, and treatments that are of uncertain or controversial benefit. Only treatments that offer no physiological benefit should be labeled futile. Futile treatment, so defined, is rare and seldom disputed. On the other hand, there are many treatments that have extremely unlikely, extremely costly or extremely marginal benefit that would best be considered inappropriate or inadvisable to offer. Given that individuals have different goals and values, any policy to limit non-futile treatment should be developed with the participation of all interested parties. As the SCCM reasoned, treatments that prolong the time until death may be viewed by some as useless or even harmful because the treatments prolong dying or suffering. For others, these treatments may be viewed as valuable since they allow family members to share the experience of death, provide an unlikely yet desired chance of survival, or are in keeping with religious beliefs. The SCCM proposed that any policies to limit inadvisable treatment should be on public record and widely distributed in the community where the hospital is located prior to implementation.

Moreover, they should reflect moral values acceptable to the community, not be based exclusively on prognostic scoring systems, detail the mechanisms by which the policy was developed and the signatories to its creation, articulate appellate mechanisms and procedures and be recognised by the courts. If followed, specific guidelines published in this consensus statement should ensure that resource allocation and treatment policies, in highly developed and less developed countries alike, are more explicit, rational, fair and democratic.

In 1997, RCPCH[21] in the UK published a framework for practice in withholding and withdrawing life-sustaining treatment. The Report's most valuable contribution lies in delineating 5 categories in which withholding and withdrawing life-sustaining medical treatment might be appropriate and in which the goals of care are redirected. First, in the case of the brain dead child (as defined in the Report) treatment would be futile and withdrawal of current medical treatment would be appropriate. Second, it might be appropriate to withdraw current therapy and withhold further curative treatment in a child who develops a permanent vegetative state following say trauma or hypoxia, is reliant on others for care and does not react or relate to the outside world. Third, in the 'no chance' situation in which the child has such severe disease that life-sustaining treatment merely delays death and quite possibly increases suffering, medical treatment may be considered inappropriate. Fourth, in the 'no purpose' situation although a child may survive medical treatment, residual physical and mental impairment may be so great as to render it unreasonable to expect a child to bear it. The Report gives the example of a newborn with profound neurological damage following severe asphyxia where microcephaly, extreme developmental delay, blindness and quadriplegia are inevitable. Fifth, is the 'unbearable situation', which allows consideration of withholding or withdrawing treatment when the child and/ or family "...feel that in the face of progressive and irreversible illness further treatment is more than can be borne". (p. 7) Additionally, patients and parents can request a particular treatment be withdrawn irrespective of medical opinion on its potential benefit, for example a child with cancer who is offered further aggressive treatment.

In line with AAP statements, the RCPCH Report supports decision making based on the patient's best interests, collaboration between the child, parents and the health care team, the primacy of parents as the best decision makers on behalf of their child, the equivalence of withholding and withdrawal of life-sustaining therapies, and legal intervention in the face of irresolvable differences between the child, parents and the health care team. On the other hand, the Report downplays the role of ethics committees in decision making since it believes they are "...too remote from the individual case to understand all aspects" (p. 23). Further, it is surprisingly non-committal and circumspect regarding the withdrawal of artificial feeding: "withdrawal of feeding" it contends "...is often a source of considerable distress, although in certain circumstances such as permanent vegetative state its withdrawal can be accepted if it is well managed". (p. 21) However, this hesitation may be partially explained by the legal requirement in the UK to obtain the Court's authority before termination of artificial nutrition and hydration in all cases of permanent vegetative state.[61]

Finally, legal and ethical guidelines relating to withholding and withdrawing life-sustaining treatment in neonates in 7 European countries are briefly reported.[22] The countries, which form part of the EURONIC Project (a European biomedical research initiative), include France, Germany, Italy, the Netherlands, Spain, Sweden and the UK. Unsurprisingly, all countries agree that whether or not life-prolonging treatment is continued, high quality compassionate care is non-negotiable for all patients. Similarly, there is widespread agreement that aggressive treatment should be withheld if a neonate has a high likelihood of dying, irrespective of medical intervention. By the same token, all countries condone the alleviation of suffering

even if death were hastened. In contrast, differences between countries are apparent in cases where neonates would be severely impaired if they were to survive – here decision making on the basis of future quality of life is necessary. In Italy, for example, non-treatment of newborns for conditions such as a severe congenital malformation or with a poor neurological prognosis is considered a form of discrimination, in violation of the Constitution and can result in criminal prosecution. Whilst uncertainty exists in the UK about what exactly constitutes an intolerable quality of life and who should define this, the official legal position is governed by the Bolam test which asserts that a doctor is not negligent if his actions would satisfy a body of reasonable and competent professional opinion. In other words, a responsible body of medical opinion would need to agree it is not in a child's best interests to continue treatment. Likewise, in the Netherlands ultimate responsibility for deciding the best course of action lies with the medical team caring for the child. In the Netherlands doctors are not obliged to provide medically futile treatment the definition of which depends on clinical judgement. In the absence of test cases, the position regarding cessation of treatment in neonates in France, Germany and Sweden remains unclear. Clinicians therefore operate in a legal vacuum. Active intentional intervention to end life is legally prohibited in all countries. Whilst, Dutch paediatricians do occasionally assist babies to die with parental consent, the legality of these actions remains unclear. In short, the range of policies described in this ambitious investigation confirms the influence of culture, religion and historical precedent on end of life practices across Europe, with a low likelihood of developing universally acceptable guidelines in the near future. The most contested area concerns the child who could be saved but whose future outlook is incontrovertibly bleak.

In South Africa there are no published guidelines on end of life care for children. However, the Consensus Statement by the Bioethics Centre at Groote Schuur Hospital[62] on withholding and withdrawing life-sustaining therapy, along with the South African Law Commission's (SALC)[63] proposals on regulating end of life decision making, are likely to have wide-ranging implications for the care of terminally ill children. The Consensus Statement[62] recognises the central role of parents in making decisions about life-sustaining therapy according to the patient's best interest. Further, if a life-sustaining intervention is highly unlikely to promote a patient's meaningful survival, it can be considered futile. Physicians have no ethical obligation to provide futile treatment. The statement strongly recommends full documentation in hospital records of all decisions taken in respect of withholding or withdrawing life-sustaining therapy. Justification for such decisions should also be recorded. Hospitals are encouraged to develop written policies regarding initiation and discontinuation of life-sustaining interventions. Whilst the statement indicates that artificial feeding is a form of medical treatment, it is mentioned only in relation to patients in a permanent vegetative state. Whether the statement sanctions withdrawing artificial feeding in other circumstances is unclear.

By comparison, the proposed the SALC Bill on End of Life Decisions[63] unequivocally holds that life-sustaining medical treatment includes the maintenance of artificial feeding. Inexplicably, artificial hydration is excluded from this definition. Additionally, the Bill proposes that competent children above the age of 14 years, with assistance from their parents, may refuse medical treatment, including life-sustaining treatment. This clause has been challenged for its ambiguity since it is unclear whether parents could overrule a child's decision to forgo further life-sustaining treatment.[64] Whereas voluntary euthanasia is under consideration for adults, this is not an option for persons under 18 years of age.

In summary, most countries at least in the industrialised world have developed ethical guidelines to enhance best practice and improve the quality of care for neonates and children

with life-limiting conditions. Furthermore, insofar as these guidelines reflect professional opinion, they are likely to carry legal standing and, in the UK, would satisfy the Bolam test. Still, despite these authoritative policies that propose reasonably consistent courses of action regarding decisions to forgo life-sustaining medical treatment, in practice, several positions remain ethically controversial and unsettled, in particular, withholding and withdrawing artificial feeding and hydration.

Not surprisingly, any attempts to draft policies and guidelines on such sensitive issues are bound to attract criticism.[24] Policies may be interpreted as imposing unnecessary constraints on clinical practice, as being too general to be useful, as discriminating against some individuals and groups, as striking the wrong balance between law and morality, or as being patently immoral. Nevertheless Doyal and Larcher[24] argue it would be unwise to leave these decisions entirely to the moral values and biases of individual clinicians and their possibly mistaken interpretation of the law. To avoid potential conflict concerning the validity of ethico-legal guidelines, Doyal and Larcher recommend involvement, from the outset, of a wide-range of multidisciplinary decision makers in both their construction and implementation as well as re-evaluation and audit (as mortality and morbidity improve and case law alters).

2.3 Ethical Considerations in Forgoing Life-sustaining Treatment in Children

In the past 10 to 20 years a clear legal and ethical consensus has evolved in many countries that supports the right of a patient with decisional capacity or the patient's surrogate to refuse or remove unwanted medical treatment. This includes the right to refuse life-sustaining treatment. As already noted, in paediatrics parents are the primary decision makers and only in exceptional circumstances are physicians able to supersede their authority. Yet, forgoing life-sustaining treatment in infants and children raises many contentious issues. Among them are the place of do not resuscitate orders, distinctions between withholding and withdrawing treatment, ordinary and extraordinary (or heroic) interventions, and whether artificial nutrition or hydration may ever be forgone.

2.3.1 Do Not Resuscitate Orders

Cardiopulmonary resuscitation (CPR) consists of a set of techniques designed to restore circulation in the event of acute cardiac or cardiopulmonary arrest.[65, 66] In hospitals, advanced CPR is undertaken in response to an urgent call. Advanced CPR techniques may include closed chest compression, ambubagging, intubation with assisted ventilation, use of vasopressor drugs, and intubation for support on ventilation.[66]

Non-resuscitation is acceptable in several situations. Competent patients can give informed refusal after being told that, unless resuscitated, patients who suffer cardiac arrest will almost certainly die. In the case of infants and young children, parents assume the right of consent.[65] Parents may consent to a DNR order if it is in their child's best interests. The problem for a parent is deciding what circumstances warrant the judgement that death is better than continued life. Morally it is argued that non-resuscitation is compatible with respect for human dignity if a patient would be so severely and permanently impaired that he or she could not flourish in even minimal ways. Clinically, the best interest standard requires that a patient be irreversibly close to death in the short term or that resuscitation presents an unacceptably high probability of death or brain damage if the procedure were successful.[65]

Futility is a further justification for withholding resuscitation.[65, 66] If the clinical condition of the patient is such that the probability of successful resuscitation approaches zero, CPR is futile as it will not benefit the patient. In fact it may harm the patient if it is 'successful' but the patient survives with a poor quality of life. If these patients can be identified in advance, this is justification for issuing a DNR order. It is not part of a doctor's duty to administer useless or harmful treatment. A futility justification requires a high burden of proof and if there is significant uncertainty about the likely outcome, resuscitation must be attempted unless a parent has indicated it would not be in a child's best interests. Some argue that if CPR is not medically indicated, it need not be offered as an option to a patient or parent and thus consent is not required. Those who reject this position claim it violates the standard of informed consent, that a patient or surrogate should always have the right to refuse or choose CPR because the quality of the patient's surviving life is a judgement the patient or surrogate alone should make.[66] Doctors traditionally see complex situations from a uniquely medical perspective, and may ignore important factors related to parents' values and preferences. Rarely is the question of whether or not to perform CPR a purely medical one. Additionally, those who support consent argue there is a lack of consensus on what probability of survival constitutes futility. Furthermore clinicians apply a concept of futility inconsistently. Finally, unilateral decisions may be biased against vulnerable populations.[66]

A DNR policy should follow acceptable moral and legal dictates, whilst optimising clinical discretion.[65] As a rule, a policy will require that CPR be a standing order, that is, it must be performed on any patient who suffers a cardiac or respiratory arrest.[66] Only when a specific order is issued that CPR is not indicated may it be omitted. A DNR order implies that if a patient suffers a cardiac arrest, the crash team will not be called and neither basic nor advanced CPR will be given. It has no implications for any other clinical decisions concerning a patient's management.[66] In other words, a DNR order does not mean that treatment and/or care should be terminated. DNR orders should be clearly and prominently documented in a patient's medical and nursing notes.[65] A DNR order should include the medical facts and clinical justification for the order, the date of issuing the order, and a summary of the discussion with the family, including informed consent. The status of the DNR order should be reviewed at regular intervals. DNR policies developed by hospitals should be open to public scrutiny.[65]

Patients with a DNR order are generally very ill and often experience a variety of medical needs that are not covered by the DNR order yet ought to be addressed. For example, being attentive to the analgesic needs of dying patients or decisions regarding continued use of antibiotics have immediate relevance to clinical care.[67] Decisions to withhold, withdraw or initiate interventions other than resuscitation should be noted in specific orders. To this end, procedure-specific DNR orders have recently been introduced as alternatives to traditional DNR orders.[68-72] By focusing on procedures, the form addresses in very concrete terms exactly what will or will not be done if a patient arrests. Mittleberger and colleagues[68] found, for example, that the number of ambiguous DNR orders decreased from 88% to 7% after implementation of a procedure-specific DNR order form. This approach to DNR orders appears particularly well suited for communication and management of patients cared for on busy hospital wards, by many different caregivers.

2.3.2 Withholding and Withdrawing Life-sustaining Treatment: A Moral Distinction

In discussions about life-sustaining interventions, physicians and parents may draw distinctions that seem intuitively plausible but prove problematic on closer analysis. Commonly drawn distinctions between withholding and withdrawing life saving therapies are examined in this

section. Most ethicists[73] and courts[74] recognise that withholding and withdrawing life-sustaining treatment are morally equivalent. Yet many clinicians are less comfortable withdrawing than withholding life-sustaining treatment, largely because the former can be characterised as an omission whereas the latter is seen as a deliberate act. Despite the psychological differences between these situations,[73] one can be ethically and legally responsible for an omission, for example, when one has a duty to perform an act that has been left undone (a railway official who fails to warn a passenger of an oncoming train); and, a deliberate action that contributes to or makes possible death may be ethically and legally permissible (action in self-defence, highly risky/ experimental surgery). Caregivers should not rely solely on their medical biases or their moral instincts in making end of life decisions, since these can lead to inappropriate care for dying children.

Despite this moral equivalence, surveys repeatedly show health care professionals believe there is a morally significant difference between stopping and not starting life-saving treatment. In a convenience sample of health care professionals attending a conference of the Critical Care Society, a minority (43%) of respondents believed withholding treatment was ethically more acceptable than withdrawing treatment, and 26% of respondents were more disturbed by withdrawing than withholding therapies.[75] In another attitudinal survey, 66% of hospital-based doctors and nurses felt there was an ethical distinction between withholding and withdrawing life-sustaining.[76] Further research[77] using case vignettes to assess attitudes to end of life care found that almost three quarters of physicians and medical students thought withholding and withdrawing treatment were different. Recent survey data confirm these earlier findings. Only 1 in 5 hospital and hospice nurses surveyed in the UK thought withholding and withdrawing life-supportive care were equivalent. [78] Comparative figures from the USA found only one third of doctors and nurses considered stopping and starting treatment similar. Less than half of European physicians surveyed felt there was no ethical distinction between withholding and withdrawing intensive care from a neonate.[79] Rates of agreement were country-dependent: Lithuania (54%), Sweden (48%), Netherlands and Estonia (35%), France and Italy (33%), Spain (32%), Germany (31%) and Hungary (21%). Together these studies suggest health care professionals are more comfortable withholding than withdrawing life-sustaining interventions. Professionals' beliefs appear to differ substantially from the recommendations of professional bodies and from majority opinion in bioethics. Several reasons contribute to this view.

First there are psychological reasons.[16] Sometimes initiating a treatment creates expectations in the minds of the health care professionals, parents and patients that the treatment will be continued 'indefinitely' or until the patient is cured. When the treatment does not work as expected or hoped, a decision to stop the treatment can contribute to feelings of disappointment, guilt and failure on the part of doctors and nurses. Furthermore, should a child die following the withdrawal of treatment, some doctors and nurses feel they are responsible for bringing about the death, more so than if treatment had never been started in the first place. Moreover, withdrawing life support can be an emotionally devastating experience. Against this it is argued that, as with all promises, doctors and nurses must take care when initiating a treatment to explain the indications for its discontinuation. They could also modify preconceptions with continuing reevaluation and education during treatment. Second, health care professionals are trained to treat diseases and cure patients.[80] This bias to treat may lead health care professionals to believe that anything less than 'going all out' to prolong lives is tantamount to abandoning patients. The technological imperative gains increased psychological and moral weight in cases where treatment has been continued for sometime, but without expected success. Third, there are legal concerns.[74] Practitioners feel vulnerable to scrutiny, potentially leading to criminal or professional proceedings.[81] Withdrawing a

treatment seems to be a deliberate action which, when it is likely to end in death, may seem more serious than an omission that ends in death. For example, discontinuing the ventilator requires a positive action, whereas not starting the ventilator seems more passive and may therefore be considered less reprehensible.[16]

However, in clinical medicine, accepting the distinction between withholding and withdrawing medical treatment as morally significant may have unintended consequences. Health care professionals may become unduly reluctant to begin some treatments precisely because they fear they will be locked into continuing treatments that no longer benefit the patient.[16] Yet additional information may become known only once treatment has started. Typically, decisions to initiate life-sustaining treatment are made when a patient's prognosis is uncertain. For example, a time-limited trial of mechanical ventilation may be appropriate for a critically ill child. If a treatment proves ineffective after several days, then it becomes pointless to continue. However, if physicians could not stop a treatment once it has begun, they might be reluctant to attempt treatments that might be beneficial. Even if a subsequent decision is to withdraw the treatment, and in so doing possibly hasten a child's death, the withdrawal of a life-sustaining treatment that proves futile or contrary to a patient's best interest is morally preferable to not having tried the treatment at all.[16]

2.3.3 Ordinary versus Extraordinary Treatment

Some clinicians[76,78] believe the distinction between extraordinary and ordinary interventions is helpful in making decisions. Interventions that are highly technological, invasive, complicated and expensive are generally considered extraordinary or heroic. Examples include mechanical ventilation and renal dialysis. In contrast, ordinary care, which includes antibiotics, intravenous fluids and tube feedings, is considered basic care or a standard nursing measure. The presumption is that providing treatments classified as ordinary is mandatory whereas it is morally permissible to forgo heroic measures.[89] But this is essentially a circular argument, since it claims that ordinary treatments are morally required because they are ordinary, and extraordinary treatments are morally optional because they are extraordinary.[16] Rather than focusing on the nature of the technology, it is preferable to balance the benefits versus the burdens of a particular intervention in a particular patient. If the burdens outweigh the benefits then the treatment is not obligatory.[73] The benefits and burdens of an intervention will vary depending on a patient's condition. Whereas mechanical ventilation is highly beneficial for a child after cardiac surgery, it may be less beneficial and burdensome in an infant with chronic lung disease.[16]

2.3.4 Artificial Nutrition and Hydration

Decisions about artificial feeding and hydration are more controversial than decisions about other life-sustaining treatments. Many physicians, treating adults and children alike, believe basic humane care requires that patients always be given food and water.[15, 80] However, nutrition and hydration may be provided with varying degrees of invasiveness. Artificial feeding, for instance, encompasses the administration of nutrients by peripheral or central intravenous lines, nasogastric tubes or gastrostomies. Stopping technologically supplied nutrition and hydration is contentious in adult and paediatric medicine. Forty two percent of physicians and nurses who cared for adult patients felt strongly that food and water should never be discontinued, even if ventilatory support and dialysis were withdrawn.[76] Despite this reported reluctance to stop nutrition and hydration, almost half the respondents believed the burdens of continuing nutrition and hydration to a terminally ill patient could outweigh the

benefits of prolonging life. About one third of clinical nurse managers of ICUs in the Yorkshire region of the UK report policies that approve withdrawal of artificial nutrition and hydration.[81]

Findings suggest this issue is even more difficult for paediatricians. A survey of members of the Child Neurology Society found that 75% of respondents 'never' withhold fluid and nutrition from infants and children in a permanent vegetative state.[17] A 1990 unpublished survey[15] of the Pediatric Section of the SCCM found that 58% of the sample would not withdraw tube feedings from a 4-month-old infant who was comatose, unresponsive and ventilator-dependent 1 month after an unexplained cardiorespiratory arrest even when the parents insisted that all treatment be terminated, and when all clinicians agreed the child would not make a neurological recovery. When parents were described as not insisting that the child be allowed to die immediately the percentage of respondents who would not withdraw food and water increased to 65 percent. In comparison, using the same case study, only 14% and 2% respectively of respondents would oppose forgoing ventilation or CPR. Likewise, another study[36] of 3rd year paediatric residents' attitudes towards life support of patients in a permanent vegetative state, revealed that all respondents would withhold vasoactive drugs, 97% would withdraw ventilation, but only 45% were prepared to withdraw IV nutrition and fluids. In a PICU-based prospective survey[44] of caregivers' attitudes towards limitation of aggressive care, only 1 in 4 respondents would consider forgoing total parenteral nutrition (TPN) from patients identified as requiring some form of treatment restriction. In contrast, 94% and 83% respectively would limit CPR and haemodialysis. The authors' explanation that physicians seem to prefer to forgo interventions that would most likely not be successful or were highly invasive is unconvincing since TPN is both invasive and carries a high risk of infection.

Several reasons are proffered as to why paediatric patients are perceived and treated differently from adults with respect to medically provided nutrition.[15] Foremost there is the symbolic importance of feeding dependent children, in particular infants. Many would argue that depriving a healthy child of food and water is cruel and inhumane. Feeding is the first response of the community to the needs of the newborn and remains a central mode of nurture and comfort. Indeed, food and water are not only goods that preserve life and provide comfort, they are symbols of care and compassion. Furthermore, even low levels of hunger and thirst experienced by most people are remembered as decidedly unpleasant. However, Nelson and co-authors[15] reject attempts to move from customary practice and emotional reaction to a moral conclusion that it is always wrong to forgo medically provided nutrition and hydration in children. It is morally incorrect, they argue, to confuse beneficial provision of food and water to otherwise healthy children with provision of medical nutrition and hydration to children with profoundly diminished life prospects and who are unlikely to benefit from its provision. Nor is being dependent on others for nutrition necessarily a morally decisive factor. If it were, it would be just as wrong to deprive a critically ill or demented adult of nutrition as it would be to deprive a child. Additionally, medical provision of nutrition and hydration cannot be equated with providing otherwise healthy children with food and water. Artificial feeding and hydration generally requires skilled medical and nursing care, involves some medical risks and complications, and is used to combat or cope with a disease process that inhibits a child's ability to swallow or tolerate normal feeds. Further, it is primarily intended to supplement nutritional intake or support nutritional and fluid needs for a limited period of time until a patient's underlying condition improves. Accordingly, artificial nutrition and hydration is more similar to medical treatment than to basic care and ought to be evaluated as such.[80]

Still, because food and water are so central to life and survival, it becomes very difficult to consider them with the same emotional detachment as one might feel toward a ventilator or

dialysis machine. As one mother,[82] with full understanding of the bioethical and legal arguments, recalls when she and her husband had to decide whether artificial nutrition and hydration should be withdrawn from their brain damaged, comatose infant son: "...although we had decided that death was Michael's best option, we were reluctant to let it happen by withholding nutrition. We fed him not because we expected his life to be improved but because we could not bear to see him 'go hungry'...the nasogastric tube was placed and feeding was done, probably more to assuage our feelings than to help him." (p.264)

Other reasons that might explain clinicians' reluctance to forgo medical nutrition and hydration are similar to those against withholding and withdrawing life-sustaining interventions generally. These include diagnostic uncertainty, children's lack of independent decision making capacity (thus their values or wishes about treatment are unknown), and the widespread belief that children are not supposed to die.[15] Although, on balance, the provision of technological nutrition and hydration is beneficial for most children, the circumstances in at least some cases (for instance permanent vegetative state and anencephaly) are such that this form of treatment is contrary to the child's best interests.

Interestingly, Childress[80] sees some value in the symbolic connection between care and nutrition or hydration. If decision makers worry over withholding or withdrawing medical nutrition and hydration, they may think more deeply about circumstances that putatively justify their decisions. Ultimately, this critical inquiry may yield the sad but justified conclusion that a patient will be best served by not using medical procedures to provide food and fluids. By the same token, these same commentators remind us that providing nutrition and hydration may sometimes be necessary to keep patients comfortable while they are dying though it may temporarily prolong dying. In such cases, artificial nutrition and hydration constitute warranted palliative care. In short, medical nutrition and hydration do not seem to be distinguishable in any morally relevant way from other life-sustaining medical treatments, which may sometimes be withheld or withdrawn from children.

In summary, decisions to use, to forgo, or to discontinue treatment should be taken as a function of and not in isolation from the clinical goals of a patient's total treatment plan. Thus the most widely accepted and satisfactory framework for thinking about whether an intervention may be withheld or withdrawn including artificial nutrition and hydration is to inquire about the balance of benefits versus burdens for a particular intervention in a particular patient. However, judgements regarding benefit and harm are themselves inherently evaluative. A decision that the burdens of a life-sustaining treatment are disproportionate to the benefits includes clinical judgement and a non-medical determination of how valuable it is to continue living. Clearly, doctors ought not to make these judgements alone, since they may be strongly influenced by their own religious, professional, and sociological backgrounds. Accordingly, public policy, in the form of the law and professional norms, recognises parents as central decision makers in determining whether a life-sustaining treatment will benefit or harm a child. Parents are expected to base their decisions on the best interest standard. Derived from the ethical principle of beneficence, the best interests of a child are usually presumed to be life preserving, but in the face of irreversible illness, this presumption requires careful exploration. Best interests may require a plan of care that focuses on the child's need for comfort and symptom relief, rather than the provision of life-saving medical therapy, to ease the process of dying in a way that promotes the comfort and dignity of the child.

2.4 Empirical Studies of End of Life Decision Making among Children Dying in Acute Hospitals

Knowledge of the process of dying in acute hospitals, including why and how life-sustaining interventions are withheld and withdrawn, comes mainly from descriptive studies of actual end of life practices. In the absence of internationally agreed standards on end of life care, this review of empirical studies serves simply to highlight worldwide differences in practice. Variations include, among others, where in hospital children died (for instance, a general ward or the PICU), treatments commonly restricted, rationales for DNR orders, and whether parents were involved in decision making. A few studies that examine end of life care for children with chronic diseases are presented first, followed by empirical reports of end of life care for hospitalised neonates and children. Noticeably missing is published research on end of life care for children with HIV/AIDS.

2.4.1 End of Life Decision Making in Children with Chronic Diseases

Several studies have examined terminal care for children with specific chronic diseases. In 1997 Robinson and co-workers[9] reviewed the medical records of 44 children with cystic fibrosis who died over a 10-year period in the Children's Hospital in Boston, USA Final hospitalisations ranged between <24 hours and >30 days. All patients had a documented DNR order and most (98%) died in hospital in a general ward (89%) and most (98%) had family members at the bedside at the time of death. The authors describe their model of terminal care as a mixture of preventive, therapeutic and palliative care. In the last 12 hours, for example, 72% of children received oral vitamin preparations to prevent future complications of CF, 75% and 36% of children respectively received IV antibiotics and chest physiotherapy to reverse or forestall current lung disease, and 86% of patients received palliative care, particularly opiates for chest pain and dyspnoea. The writers justify this approach on several grounds. Therapeutic interventions, such as IV antibiotics, have a relatively low morbidity and thus the health care team is willing to continue these therapies. Furthermore, they may actually be useful in reducing respiratory symptoms. And since these children have received similar treatment regimens most of their lives, continuation is not such a burden and may even provide physical and psychological support, at least according to the researchers. As a methodology, chart review can only reveal the documented practices of the doctors and nurses, thus it is not possible from this study to determine patients' or parents' points of view. Conceivably, they could have reached opposite conclusions. They could reasonably have preferred to forgo all tubes and invasive procedures especially since the patients were dying.

In another study[83] that examined all CF deaths in Canada in 1996, the authors confirm how difficult it is for clinicians to know when to change the goals of therapy. Patients may have several admissions to hospital for treatable chest infections in their last few months of life. Thus to control symptoms caused by underlying infection, it may be argued that patients should be actively treated even in the terminal phase. A high proportion (78%) of patients died in hospital, 16% of whom died in the intensive care unit. Seventy six percent of patients received palliative care, which included morphine (34%). In keeping with the previous study, the needs of CF patients and their families were not evaluated.

In contrast, parental perceptions regarding end of life care for children who died of cancer were examined.[8] Based on interviews with 103 parents of children who died of cancer, Wolfe and her team found that 89% of the children suffered 'a lot' or 'a great deal' from at least one symptom in their last month of life, most commonly pain, fatigue and shortness of breath.

Compared to data extracted from medical charts, parents were significantly more likely than doctors to report symptoms of suffering. Palliation was far less successful among children who died of treatment-related complications rather than progressive disease. As long as the primary goal of treatment was cure, concerns about quality of life received little attention. This led researchers to conclude that even when aggressive treatment directed at cure is undertaken in children with a low likelihood of long-term survival (66% of children had a DNR order), concurrent attention to palliation is essential. The researchers acknowledge that parental perceptions may not accurately reflect the actual experience of their child. Still, in paediatrics, parental perceptions command attention.

An important theme common to these studies, with direct relevance to end of life care for children with HIV/AIDS, is the impact of uncertainty on end of life decision making. Faced with prognostic uncertainty, doctors adopted a mixed management strategy, which combined aggressive management of underlying disease with palliative management of current symptoms. Whereas doctors seemed satisfied with this approach, parents of children who died of cancer reported considerable suffering at the end of life.

2.4.2 End of Life Decision Making in Neonates

An extensive literature exists on end of life decision making in the newborn and neonatal period. Treatment dilemmas arise mainly around the complications of prematurity and treatment of severe congenital anomalies[14] and are therefore beyond the scope of this thesis. Still, it bears mentioning that the proportion of neonates dying in neonatal intensive care units (NICUs) following a decision to forgo life-sustaining treatment is steadily climbing. Whereas rates ranged between 10% and 30% in the 1970s and 1980s, recent data show that as many as 87% of deaths in the NICU are preceded by a decision to withhold or withdraw treatment. [26] Other relevant data come from a European multicentre study of physicians' self-reported attitudes[79] and end of life practices[25] in NICUs. The EURONIC Project provides the first reliable evidence of the role that different cultures and legal and religious contexts play in end of life decision making. Stringent statistical analysis confirmed a physician's 'country' as the strongest predictor of differences in attitudes to end of life care and actual end of life practices, followed by physicians' religion, which was generally linked to country.[79] For instance, clinicians, from predominantly Catholic countries, who assessed religion as extremely or fairly important in their lives, were significantly less likely ever to have withheld intensive care or withdrawn mechanical ventilation. The role of 'country' is illustrated in other examples. In the case of an infant in pain with little chance of recovery, most respondents in every country (France, Germany, Luxembourg, the Netherlands, Sweden and the UK) except Italy were prepared to accept the risk of death as a side effect of analgesia. In contrast, only respondents from France and the Netherlands reported having made a decision to administer drugs intended to end a patient's life. On the other hand, most physicians in every country considered mental disability to be an outcome worse than death, and all agreed the burden on the family is relevant when making end of life decisions for a child. About one third of physicians in the Netherlands, France and Estonia saw no ethical difference between treatment withdrawal and administering drugs with the intention of ending a patient's life, that is, active euthanasia.

An attitude scale comprising physicians' responses from each country was constructed.[79] Physicians with the most pro-life attitudes came from the Balkans, Hungary and Italy, whilst physicians from the UK, the Netherlands and Sweden held the most pro-quality of life views. Consistent with these differences, physicians in Italy and Hungary were significantly less likely

to recommend limiting intensive care in patients who were neurologically devastated. Fear of legal consequences affects decision making. For example, Italian law, which protects children to the extent that it is mandatory to resuscitate a birth that results from a late abortion, severely constrains decisions to forgo life-sustaining interventions. That only one third of physicians in Italy supported a statement favouring sanctity of life regardless of prognosis seems to confirm a strong legal influence, which overrides personal attitudes.

In sum, although based on self-reported attitudes and practices of physicians in NICUs, the impact of culture on end of life decision making is likely to cross all age levels. Moreover, depending on the physician's culture, critically ill neonates and children could face markedly different attitudes about restriction of life saving interventions. Widespread variation in the rates and nature of end of life decision making across countries should stimulate international multicentre studies to determine whether differences lead to mainly over-treatment, under-treatment or acceptable standards of end of life care. Such data, which could include ethical analysis, could help standardise and improve end of life care for newborns and children. These findings point to the importance of parents as primary decision makers for their children. If doctors make crucial end of life decisions, these decisions may be strongly influenced by doctors' biases, which may stem from, among others, religion or the doctor's country of origin.

2.4.3 End of Life Decision Making in Children

Descriptive studies of end of life decision making in children dying in hospital are presented in chronological order of publication.

A prospective chart and interview based study of 50 consecutive deaths in the PICU of the Children's National Medical Center in Washington, D.C. revealed that 32% of deaths were preceded by a decision to withhold or withdraw therapy.[27] Mechanical ventilation was the most common therapy that was discontinued, followed by inotropic support or both. In line with hospital policy, all patients in whom treatment was withdrawn had a DNR order. All DNR orders were discussed with parents or legal guardians before documentation.

In 1993 Lantos and colleagues[28] reviewed 54 medical records of patients who had died in a Chicago Children's Hospital to determine the frequency and describe the circumstances in which DNR orders were written. At least 4 in 5 deaths occurred in the PICU. One third of patients had a written DNR order at the time of death. Most (91%) DNR orders were charted after discussion with the family. At least 1 intervention, mainly mechanical ventilation, chemotherapy, inotropes or blood transfusion, was forgone in 44% of patients with a DNR order.

Likewise, Ryan and colleagues[29] examined modes of death in a PICU in Alberta, Canada over a 2-year period. Approximately half the deaths occurred as a result of withdrawing treatment (34%) or after a no-CPR decision (15%). Significantly, no decisions were taken on the basis of resource allocation or parental financial constraints.

In a prospective study Leveton and co-workers[30] examined the types of treatment limitations placed on patients admitted to 16 PICUs. Limitations were evenly distributed between DNR orders (39%), additional limitations beyond DNR orders (27%), and withdrawal of medical interventions such as mechanical ventilation and inotropes (34%). Following Mink and Pollack,[27] the most common justification for the restriction was imminent death of the patient. Physicians' disinclination to use quality of life justifications puzzled the research team, since

half their sample comprised children with serious underlying chronic or lethal disease. They postulated that physicians might have been uncomfortable predicting future quality of life for young children, or that physicians may have reported what they perceived as the least controversial justification, even when other justifications may have been more accurate.

A retrospective chart review[31] over a 24 month period of all deaths in the PICU of Great Ormond Street Hospital for Children, London revealed that 65% of all deaths resulted from decisions to withhold (15%) and withdraw (50%) life-sustaining interventions. Mechanical ventilation was most commonly withdrawn. One third of patients had a DNR order in place prior to treatment limitation. Fifty four percent of deaths in a study of 9 PICUs in France resulted from treatment limitation.[32]

Goh and fellow researchers[33] provide rare evidence of end of life decision making in a PICU in a developing country. Data were collected using retrospective chart review of all admissions to a Malaysian PICU over 2 time intervals (1995 and 1997-8). Surprisingly in the light of previous data, decisions to withhold treatment (no-CPR or no intensification of current management) were far more common than decisions to withdraw mechanical ventilation (46% versus 5%). The 'no chance' situation or imminent death was cited as the reason for withholding care in 95% of decisions. Two thirds of parents who were offered the option declined extubation and opted for other forms of treatment limitation. Paediatricians initiated end of life discussions with parents in 95% of cases. Whilst the extended family was generally always present, nurses participated in less than one quarter of discussions. That said, self determination has less value in Malaysia than most Western countries. Parents and extended family trust doctors to make decisions for them in their child's best interests, an arrangement, which the authors describe as 'paternalism with permission'. The researchers attribute the slightly lower rates of withholding treatment and hence continuation of aggressive interventions, to diagnostic uncertainty, presence of iatrogenic complications and, to a lesser extent, fear of litigation. On the other hand religious factors accounted for the very low proportion of patients from whom treatment was withdrawn. The authors point out that treatment withdrawal is very difficult for families to accept even if life is being maintained by artificial means only. For these families death is an inevitable point not an option. Whilst these clinician-researchers seem less affected personally by local religious beliefs, their findings confirm reports from European NICUs where religion similarly affected end of life decision making.

In 1999 van der Wal and co-workers[34] retrospectively investigated deaths, covering a 4-year period, in a tertiary children's hospital in the Netherlands. Twenty two percent of patients in this series died in a general ward. In fifty three percent of deaths some form of life-sustaining intervention was limited. Respectively 14% and 39% of patients had a DNR order (as a single restrictive order) and treatment withheld or withdrawn. In line with previous reports,[30, 33] imminent death was the most common justification for forgoing life-sustaining treatment, followed by excessive burden due to a chronic disease (41% and 30% respectively). The most common modes of forgoing treatment were withdrawal of mechanical ventilation and inotropes.

Broadly speaking, palliative care services for children are rare even in well-resourced countries. Therefore McCallum and co-researchers[35] examined the course of terminal illness and symptomatology in children who potentially might have benefited from such a service. The sample was drawn from all children who died in hospitals in Edmonton, Canada between January 1996 and June 1998. Children known to be terminally or chronically ill and who were hospitalised for at least 24 hours prior to death were included. Children who died after an acute event and who were hopsitalised for at least 7 days prior to death were also included.

Data were abstracted by chart review. Most (87%) died in intensive care units. Sixty six percent of patients had a DNR order. Consistent with earlier research,[30, 33, 34] imminent death or futility was typically given as a reason for withholding or withdrawing treatment. Treatment was withdrawn in 43% of patients.

Failure to include parental perspectives is often identified as a shortcoming in studies of end of life practices. With this in mind, Meert and colleagues[84] sought the views of 78 parents whose child had died in the PICU of the Children's Hospital, Michigan, USA. Forty one (52.5%) of 78 parents recalled discussing treatment restrictions with their child's physicians. Physicians initiated most (90%) discussions and many (66%) parents were very satisfied with proceedings, especially where physicians were skilled communicators. When faced with an option to limit treatment in their terminally ill child, parents identified the physician's recommendations, the diagnosis, expected neurological recovery, and degree of pain and suffering as extremely important factors in decision making.

In summary, these empirical studies reflect a wide range of end of life practices across an equally broad spectrum of countries. The dearth of data from developing countries is striking, though not necessarily surprising since interventions are, broadly speaking, less likely to involve high technology medicine on a large scale. Moreover, many developing countries cannot afford to undertake and publish research that examines end of life practices. Retrospective chart reviews, small sample sizes, absence of consultation with parents, and differences in case mix and interpretations of resuscitation are among the methodological shortcomings in many studies. Still, the combined data suggest that withholding and withdrawing life-sustaining therapies is becoming more common, with rates ranging between 32% and 60%. DNR orders occur frequently, with imminent death a common justification for limiting life-sustaining medical support. However, in retrospective surveys, ethical reasoning concerning treatment restrictions is difficult to assess or often is not documented at all. Quality of life assessments in particular may not be recorded because they are too subjective or physicians fear medical and legal liability. Concerns about cost or distributive justice did not appear to explicitly affect decisions to limit treatment. Despite methodological flaws such as selection bias and reliance on recall, 2 studies[8, 84] shed some light on parental perspectives regarding end of life practices. Generally, parents want to share in end of life decision making, although the degree is an individual matter, and they certainly want to be kept well informed. Indeed, paediatric oncologists from the US, Canada and the UK report the second most important reason they shifted from curative to palliative care was parental or patient insistence they stop treatment.[85] Similarly, Meert *et al*[84] report only 1 parent who did not want any decision making authority. Yet these findings, admittedly from a culture that values self-determination, do not square with those of Goh *et al*.[38] In a developing world context, where parents are often poorly informed about medical matters and where religious convictions are important, these researchers[38] encountered a tendency towards 'paternalism with permission', where decision making powers are returned to paediatricians. Considering the scale of the epidemic worldwide, it is striking no empirical studies have yet examined end of life among terminally ill children with HIV/AIDS.

2.5 Palliative Care and Pain Management in Infants and Children

2.5.1 Policies on Palliative Care and Pain Management in Infants and Children

Interest in the quality of care at the end of life has come from numerous quarters in organised medicine and the lay community. In particular, the hospice movement, by defining and

providing care for dying patients, has stimulated the development of the discipline of palliative care. Interest in palliative care[86-89] and pain management[90-93] in children is now also firmly established and guidelines for the provision of paediatric palliative care services and pain management have recently been published by the American Academy of Pediatrics[47] and a Joint Party of the Association for Children with Life-Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health.[45] A related development directed towards improving standards of health care in hospitals, including better pain management, in less well-developed countries is welcome testament to a global concern aimed at relief of pain and suffering among all children.[94]

Published guidelines[45-47] on palliative care have much in common. Directed towards children who are not predicted to survive into adulthood, palliation is an approach to care that is foremost child-centred and addresses patients' needs within the context of the family and the community. The goal of care is the best quality of life for the child and family in line with their values, preferences and beliefs. Palliative care places a high priority on the control of pain and other symptoms and addresses psychological, psychosocial and spiritual problems facing dying children and their families. Palliative care should be accessible to children and families in several suitable settings such as the home, hospice or intensive care unit. Paediatric palliative care is optimally delivered by an interdisciplinary team including paediatricians, nurses, social workers, pastoral caregivers and trained volunteers. It should include an identified, accessible and accountable key worker to assure that children and parents receive seamless, continuous care, which includes regular and consistent communication. Palliative care should be available to the patient and family 24 hours a day, 365 days of the year. Palliative care is emotionally draining and direct caregivers should have access to psychological support and supervision. Finally, it may include respite care, telephone support, grief counselling following a child's death, and referral to community resources.

Importantly, guidelines reject rigid distinctions between curative, life-prolonging and palliative interventions as these may hinder the timely and appropriate provision of palliative care to children with a terminal condition. If the nearness of death is used to determine if children receive palliative care then some children may die without the benefits of this approach. An assumption that there is no place for palliative care until all curative options have been exhausted may deter an early discussion of palliation, including limitations of unduly burdensome interventions at the end of life. If parents (and patients) infer that discussion of, say comfort care, is equivalent to 'giving up' they might be inhibited from raising concerns and fears about the burdens of life-prolonging interventions and the dying process.[47] Therefore, components of palliative care should be offered at diagnosis and continued throughout the course of illness whether the outcome ends in cure or death. The AAP[47] and RCPCH[45] also recommend that certification boards and fellowship training programmes place greater emphasis on, among others, palliative medicine, communication skills, managing prognostic uncertainty, grief and the spiritual dimensions of life and illness.

A combined statement by the American and Canadian Pediatric Societies[46] and a Consensus Statement by the International Evidence-Based Group for Neonatal Pain[48] specifically address pain management in neonates. These statements emphasise that neonates do feel pain, which can be accurately assessed using reliable and validated measuring tools. Exceptions include very low birth weight babies and neonates receiving mechanical ventilation for which no satisfactory measuring instruments are as yet available. The statements support the use of opioids to control moderate and severe pain in neonates provided personnel are skilled in neonatal airway management and necessary equipment is available for continuous monitoring.

Led by Anand,[48] a world-renowned expert on pain management, the international panel has produced guidelines for management of pain based on the best available scientific evidence. These guidelines can be adapted for individualised care plans and analgesic protocols for specific clinical situations, patients and health care settings.

Although modern technology and treatment regimens in well-resourced countries have improved survival of sick children, most children in the rest of the world lack access to adequate health care of any kind. Many hospitals in developing countries do not have basic water, sanitation, an electricity supply or even minimal security. In this light, recent publication of the Child-Friendly Healthcare Initiative is pleasing.[94] Developed in consultation with local health care professionals and international bodies, including the Department of Child and Adolescent Health and Development of the World Health Organisation and the United Nations Children's Fund, the Initiative aims to develop globally applicable standards that will help ensure that practices in hospitals respect children's rights not only to survival but also to protection from unnecessary suffering. Currently the scheme is being piloted in Uganda, Nicaragua, Afghanistan and Bosnia. The Working Party of CFHI, under the auspices of Child Advocacy International, has developed 12 provisional standards to improve health care delivery. Standards No.6 and No.7 pertain directly to improved pain management. Standard No.6 provides guidelines for assessment and control of pain and discomfort, using pharmacological and non-pharmacological measures, safe storage of opiates, palliative care, and individual pain control developed with the child and parents. Standard No.7 stipulates that all invasive procedures must be accompanied by adequate analgesia and when systemic analgesia or sedation is used, personnel experienced in resuscitation should be immediately available. Hospitals should also have written guidelines for pain relief for specific procedures. Ultimately, the success of the CFHI in developing countries will depend on political will and availability of resources.

2.5.2 Ethical Considerations in Pain Management in Infants and Children

Statements by the AAP[47] and the RCPCH[45] support the use of pain medication and other treatments, which may incidentally hasten death even if their primary aim is to relieve suffering. On this view, giving a medicine to relieve suffering which as a side effect may hasten death is ethically and legally justified and can be appropriate. In turn, these professional bodies reject voluntary euthanasia where the primary goal of giving medication is to hasten a child's death.

Still, many physicians fear that because medications needed to provide adequate pain relief to terminally ill patients carry a risk of indirectly or accidentally ending the patient's life by depressing the patient's respiration, this will result in possible criminal prosecution. Health care workers believe hastening death is wrong because it is killing the patient.[74] Indeed, over 40% of sampled doctors and nurses indicated they would give inadequate levels of pain medication through fear of hastening a patient's death.[76] Thirty one percent of nurse managers of adult ICUs in the UK saw no difference between active euthanasia and administration of analgesia and sedation in dosages that might heighten death even if these drugs were given primarily to ensure patient comfort during or after mechanical ventilation.[81] In response to the question: 'Does concern about respiratory distress limit the amount of narcotics you prescribe?' 63% of paediatricians, family practitioners and surgeons indicated that it somewhat (42%) or always (21%) limited their use of opioids.[95] In comparison, Wolfe[96] found that 93% of parents approved the use of morphine in a hypothetical case involving a child with terminal cancer who was in unremitting pain, even if premature death was a likely consequence. Moreover, after

experiencing the death of a child through cancer, most parents favour very aggressive pain control for a terminally ill child in pain, even at the expense of further life extension.

These fears are not justified factually or ethically. Indeed, continued philosophical debate about this doctrine inadvertently highlights the adverse effects of opiates when in fact these consequences are rare. Survival was not noticeably shortened in a hospice unit-based study of 238 patients who received opioid increases at the end of life compared to patients who received no increases.[97] From an ethical standpoint, doses of analgesics sufficient to relieve pain, which might hasten death as an unintended effect, are permissible if the conditions of the doctrine of double effect are observed.[98] This doctrine is often invoked to explain why certain forms of care at the end of life that result in death are morally permissible and others are not. Broadly speaking, the doctrine holds that when an intervention (high doses of analgesic medication) is used for a legitimate purpose (pain relief) but has an unintended effect that would be illegitimate if it were intended (the death of a patient), the physician is not morally responsible for the unintended effect (hastening death). For this doctrine, which stems from Roman Catholic moral theology, to be ethically permissible it must fulfil 4 conditions. First, the action itself must be morally good or at least morally neutral. Second, only the good effect must be intended, even though the bad or secondary effect is foreseen. Third, the good effect must not be achieved by way of the bad effect. Fourth, the good effect must outweigh the bad result. In short, the good effect (pain relief) is intended, whereas the bad or secondary effect (hastening death) is foreseen but not intended. The doctrine of double effect has been criticised for its questionable account of intention.[99, 100] Whilst the doctrine requires that primary intentions be explicit and clear, in reality they may be muddled. Put differently, some argue that it is implausible to believe that agents are psychologically disciplined enough never to wish for death to come about as a result of their action, especially in the face of a patient's intractable pain and suffering.

These criticisms notwithstanding, the doctrine of double effect has practical value and underpins policy guidelines for end of life care provided by the AAP[47] and the RCPCH.[45] In similar vein, the SALC[63] has made a legislative proposal that rests explicitly on the doctrine of double effect: if a terminally ill patient's pain and distress cannot be satisfactorily alleviated by ordinary palliative treatment, then a physician (a) with the object to provide relief of severe pain or distress, and (b) with no intention to kill shall (sic) increase the dosage of medication given to the patient even if the secondary effect of this action may be to shorten the life of the patient. If the Bill becomes law, South African physicians should be reassured that as long as they act with the intention of relieving a patient's pain and suffering, the risk of legal liability would be exceedingly small.

Philosophical and legal arguments aside, proponents of the doctrine of double effect remain convinced it offers reassurance to physicians who are then more likely to provide optimal care for dying patients.[98] Wolfe[96] recommends senior physicians directly address emotional discomfort or objections, arising from administering high doses of narcotics, through individual discussions or team meetings to help nurses and junior doctors understand the medical situation and the reasons for the decision. Such discussions also provide an opportunity to voice concerns, values and beliefs that may underlie disagreements. In summary, caregivers need to recognise administration of high doses of narcotics to relieve symptoms in patients with terminal illness may be ethically justified.

2.5.3 Empirical Studies of Pain Management in Children

A great paradox in pain management is that although the relief of pain and suffering is widely acknowledged to be a central responsibility of physicans[96, 101, 102] pain associated with many life-threatening paediatric illnesses, most notably cancer[7, 8] and HIV/AIDS,[6, 39] remains seriously undertreated. In comparison, chest pain, dyspnoea and headaches among children with cystic fibrosis have been successfully treated.[9, 103] However, since both sets of findings among patients with cystic fibrosis are based on retrospective record reviews by clinicians, it is conceivable that patients and parents may have reported lower levels of satisfaction with symptom relief. Indeed, discordant views between physicians and parents regarding presence of pain were noted by Wolfe and co-workers[8] in their study of children who died of cancer. According to parents, 9 out of 10 children experienced substantial suffering from at least one symptom in their last month of life, most commonly pain, fatigue and dyspnoea. Moreover, treatment of pain and dyspnoea was successful in less than one third of children (27% and 16% respectively).

In comparison to cancer pain in children, examination of the pain experience among children with HIV/AIDS has received minimal attention in the literature. In a retrospective chart review of 149 inpatient children (mean age: 62 months) treated in the Children's Hospital of New Jersey AIDS Program, Czarniecki and colleagues[104] gauged that 88% had 1 or more medical problems that could reasonably be expected to cause acute pain, (for example, otitis media, herpes lesions, skin lesions) or chronic pain (for example, oral thrush and oesophagitis). Yet of the 149 records reviewed, only 24% contained any notation of pain. Abdominal and extremity pain was most likely to be documented. Seven infants and toddlers were described as very irritable, with pain the presumed cause. These children were usually termed 'miserable babies'. Of the 57 documented episodes of pain in 36 patients, 35% were treated with pain medication, typically paracetamol. The authors note that although medication was charted on the medicine sheet, often it was never administered. In view of methodological problems inherent in the design of retrospective studies, it is possible these findings underestimate the extent of pain.

In a questionnaire survey[6] of 61 outpatients with HIV/AIDS (4 years to 13+ years) and their families, the reported prevalence of pain approaches 60 percent. In this group, common sites of pain were the gastrointestinal tract or limbs. Paracetamol and non-steroidal anti-inflammatories were the treatments of choice. Approximately 1 in 5 children reported that pain interfered with daily activities and sleep. Surprisingly, the incidence and impact of pain were not significantly associated with disease progression as determined by surrogate markers such as CD4 counts.

In a case report of an 18-month-old child with AIDS, Anand and co-researchers[105] express concern over doctors' reluctance to consider pain as a source of discomfort in the evaluation and management of an irritable child. In this case report, the patient had a history of oral and oesophageal *Candida, Candida* tracheitis and pneumonia. The child was sensitive to touch and cried constantly. Mild analgesia (paracetamol) was instituted only 10 days after admission and then on an 'as needed' (PRN) basis. Anand and his team of pain management specialists were not consulted until 3 weeks into the hospital course. They report that within 2 days of initiating oral morphine, restlessness improved, and the patient enjoyed quiet, undisturbed sleep. After 1 week of morphine therapy, there was no further abnormal crying or whimpering, tone was more relaxed and the patient's appetite improved. The authors conclude that clinicians may falsely attribute irritability in sick children to the effects of prolonged illness.

They contend that pain should be presumed to be a component of the complex clinical picture of children with AIDS, and empirical trials of analgesic therapy should be a critical part of any management plan.

Likewise, in a review article of pain syndromes in children with AIDS, Wishnie and Weisman[39] claim an empirical approach, which includes observing a patient's response to a trial of pain medication, is currently the best means available to judge presence of pain, especially in infants and young children. This requires careful use of analgesia in uncertain situations, followed by close observation for induced changes in physiological and behavioural states.

2.5.4 Attitudes and Beliefs about Pain Management in Children

Although many infants and children with life-threatening disease need analgesia for pain relief, these medications are often used inadequately due to misconceptions held by professionals, parents and children. [106, 107] Professional biases and false beliefs account for inadequate use of opioid medication.[106, 107] Previously it was felt that very young children's nervous systems were too immature to feel pain, that children do not remember pain, that pain produces no harmful effects in children, and may even be character-building. Further, self-reports or behavioural manifestations of pain may be attributed to separation anxiety or attempts to gain secondary benefit. Infants and younger children are at greater risk of undertreatment because they are unable to report pain or may exhibit pain non-verbally. For caregivers unschooled in pain assessment, if a child cannot describe pain or localise pain then he does not have any, and if children do not show signs of pain then they are not in pain.

Alternately, in advance of painful procedures, health care professionals may minimise the pain a patient will experience, for instance they may say: 'this may sting a bit', or 'you may have a slight headache after the lumbar puncture'. Discounting pain in this way serves 2 purposes.[108] It provides doctors with a clinical rationale to reduce a child's fear and resistance. It also helps clinicians to distance themselves from the pain they continually encounter and often produce in the course of diagnosis and treatment. Ruddick[108] further contends that medical training exacerbates physicians' undertreatment of pain. Students, he argues, are trained to regard pain as a useful symptom for diagnosing disease. Instead of relieving it, students are taught to observe and explore pain even if that involves enhancing it through palpation of soft tissues and manipulation of joints. Similarly, students learn how useful pain can be in following the course of a disease, stages of healing, or the efficacy of drug therapy. More cynically, Ruddick suggests students learn the many ways in which analgesics, especially opioids, complicate therapeutic interventions. For example, they may cause vomiting, constipation or suppress vital functions such as respiration, already compromised by severe disease. To avoid these complications, young and inexperienced clinicians may be inclined not to prescribe opioids at all.

Few of these misconceptions withstand scientific scrutiny. There is mounting evidence[46, 48] that newborns have the necessary pathophysiology to transmit painful sensations, that children at least from age 5 are accurate reporters of their own pain and with few exceptions (for example, pain associated with mechanical ventilation) reliable and valid measures of neonatal pain are now available. In light of this evidence, Walco and colleagues[109] describe doctors' failure to relieve pain as an unjustified harm. Similarly, they reject justifications that pain is useful to monitor illness or that masking pain could obscure physical signs and actually harm patients. Instead, they assert the risks and benefits of immediate relief must at all times be weighed against the burden of unrelieved pain and the prospects of long term recovery. In their opinion,

any attempt to justify withholding pain relief on grounds that pain promotes character development is ethically questionable in a child already encumbered by sickness. If it is not possible to completely eradicate pain then strengthening a child's capacity to cope is beneficial, for instance by cognitive interventions such as relaxation and use of mental imagery. Withholding analgesia from a suffering child in the hope of strengthening character ignores the child's need for immediate pain relief. And, say Walco *et al*, doctors have an ethical responsibility to fully relieve pain unless otherwise justified by defined therapeutic benefits.[109]

Lack of knowledge about pain management[110] is partly responsible for undertreatment of pain. Yet, even where doctors and nurses believe infants experience as much procedure-related pain as adults, these beliefs do not lead to adequate pain relief.[95, 111] This is illustrated by respondents' self-described pain management behaviours, which were well below optimal levels.[111] In stark comparison, 91.5% of paediatric oncologists considered themselves highly competent pain managers, with one third of survey respondents confidently reporting that none of their patients died in pain, although one half conceded 10% of cancer patients may have died in pain.[85] Despite this self-rated competence, almost 50% of clinicians admitted feeling anxious about having to deal with difficult symptoms, of whom 13.5% felt very strong anxiety. Wolfe and colleagues[8] found that relief of pain and suffering in children who died of cancer was superior when physicians were actively involved in the children's management. This included open communication about goals of treatment and benefits of palliation. Because pain management and symptom control are undisputed goals of medicine, they must be taught. Physicians who care for children with life-threatening illnesses have an obligation to be well informed and trained in palliative care.[96, 101] According to 90% of sampled paediatric oncologists,[85] trial and error learning from colleagues in clinical practice, and role models in fellowship and residency training were the most common sources of knowledge about palliation (91.9%, 85.4%, 81.8% and 64.5% respectively). What is more, trial and error was the most useful, if 'costly' from the patient's point of view, means of learning to care for dying cancer patients. Role models in subspecialty training, and learning from colleagues in clinical practice were the next most highly rated sources of learning. Only 1 in 10 paediatric oncologists had attended a formal course in palliative care.[85] Rotation through a palliative care service or hospice formed part of the training of only 2% of respondents. In general, attendees at formal courses found them less helpful than on-the-job training.

If doctors lack the skills to adequately treat pain, they have an obligation to refer the patient to a physician with specialist knowledge in pain relief and symptom control.[96] Likewise, senior physicians and health care administrators have particular obligations to ensure that trainees are educated in matters of palliation, and that suitable structures exist for provision of high quality palliative care services to patients.[96] Even in well-resourced countries such as the US, Canada and the UK, lack of a readily available and easy-to-use palliative care team or pain service was identified by more than one third of paediatric oncologists as a significant institutional barrier to optimal end of life care.[85] Still, in some countries, despite doctors' efforts, lack of access to opioids may lead to undertreatment of pain.[94] As already discussed, global initiatives to increase the priority of pain management in hospitals in less developed countries are underway.

Doctors and parents may fear addiction if children receive morphine for pain.[95, 104] Survey data[95] show that almost 2 in 5 physicians worry about the risk of addiction from the use of narcotic analgesia in children. Since intravenous drug abuse is an important cause of HIV transmission in some countries, doctors in these countries are especially hesitant to prescribe opioids for fear that parents will abuse their children's medication.[110] In a review article of pain

management in children, McGrath[106] found no evidence of abuse associated with use of narcotic medication. On the other hand, Llungman *et al*[7] found no evidence that opioids were withheld from children with cancer because parents feared addiction. Overall, addiction is probably rare in children receiving narcotics for medical indications, and if a patient is terminally ill then fear of creating addiction is misguided. Rather, an overestimation of the risk of analgesic induced addiction leads to an underestimation of the harm of untreated pain.[109] If analgesics are administered properly, the risk of addiction is minimal.

Significantly, a recent review of adverse sedation events,[112] such as death and drug abuse, found no relationship between outcome of drug use and drug class (for instance, opioids). Instead adverse events were associated with overdosing, drug combinations and administration by non-medically trained personnel. Rather than restrict use of opioids for pain relief, physicians must ensure they understand the pharmacology of a particular drug and how to manage expected drug-related complications. By the same token, research data[88] suggest that with adequate monitoring and adherence to published guidelines for dosages, side effects such as respiratory distress from opioid overuse are rare. Moreover, research shows that long-term use of opioids for chest pain in children with cystic fibrosis does not lead to dose escalation or respiratory distress.[103] If respiratory distress does occur, then potent agents are available to reverse adverse effects of opioids. If a parent indicates that the reason for refusing to use narcotics is fear of addiction, the doctor must dispel irrational beliefs and strongly recommend the child receive such therapy.[96]

Finally, pain may be denied or understated by parents who fear that pain represents a recurrence of an underlying disease, for example cancer.[106] Conversely, unrealistic physician and/or parental prognostic expectations may lead to inappropriate treatment goals that focus on curative treatment instead of treatment that lessens suffering.[113] In a study of children who had died of cancer, parents' understanding that their child no longer had a realistic chance of cure lagged behind oncologists' explicit documentation of end stage disease by 3 months. When both physician and parent recognised there was no realistic chance of cure, pain and symptom control was vastly improved.[113]

In summary, fundamental biases, limited knowledge and expertise in the use of opioids, misplaced beliefs that pain is character-building and pain medication causes addiction, held by health care professionals, parents and children, mitigate against appropriate use of narcotics in children. Professional and parental education directed towards dispelling myths and misconceptions, and improving pain relief strategies and institutional policies that make pain relief a priority should result in better pain management.

2.6 Medical Education for End of Life Care for Children

If patients are able 'to live until they die' through provision of exemplary end of life care, they may be fortunate enough to experience a good death. However, if doctors are inadequately trained to provide palliative care, patients may well endure a bad death. Thus education to improve clinicians' knowledge and skills in, among others, ethics, communication and palliation is a necessary foundation for delivering quality terminal care. Attempts to address gaps in palliative care education include publication of a status report[114] of palliative medicine in undergraduate medical curricula and recommendations on how to improve teaching about palliation in acute hospital settings,[115] including intensive care units.[116] The final section of this

literature review focuses specifically on medical education about end of life care in paediatric settings.

Khanya and Milrod[117] assessed the perceived educational needs of 74 paediatricians at 1 university hospital in New York City, one third of whom belonged to subspecialties that commonly encountered dying children, for instance oncology, critical care medicine and infectious diseases. Whilst a reasonable proportion (71%) of attending physicians (consultant paediatricians) felt adequately prepared to deal with end of life issues, little over half (56%) the fellows and only 13% of residents (registrars) felt equipped to handle death and dying. Not surprisingly, most (95%) residents and fellows and two thirds of attending physicians believed further instruction in end of life care would be useful. Moreover, all residents and 9 out of 10 attending physicians expressed a need for further emotional support in dealing with death and dying. Only 1 in 10 residents and 1 in 4 attending physicians felt there were adequate existing support structures in the department. Whilst about 3 in 5 respondents would have liked to attend funeral or memorial services, clinical responsibilities proved major obstacles for many. Almost three quarters of attending physicians working in subspecialties with higher death rates reported that they sometimes viewed a patient's death as a personal failure. In contrast, about two thirds of residents said this was rarely or never the case. The authors speculated that attending physicians' overall responsibility for patient management might have reinforced feelings of failure. This finding is worrying for if death represents failure, clinicians, especially those in charge, may be tempted to pursue aggressive therapies in hope of a 'cure' for longer than benefits their patients. Admittedly, these findings reflect 1 institution and the response rate was low (56%). Based on their findings, the authors recommend systematic teaching on caring for dying children, including hospice and palliative care rotations through out residency training. However, for most developing countries and for that matter many developed countries, their recommendation that, after a child's death, each involved health care professional should be counselled by a liaison psychiatrist, is to say the least utopian.

Another survey[118] in the Department of Paediatrics in Los Angeles examined changes in self-reported attitudes of trainee physicians during their 4-year paediatric residency. Whilst paediatric house staff are uneasy with issues of death and dying in their first 2 years, by their 3rd and 4th year of training they feel somewhat more comfortable handling these issues. Interestingly, findings show that formal educational methods such as lectures and seminars with other members of the health care team are far less helpful than clinical teaching at the bedside, for instance participation in meetings with families of children who have died or were dying. Somewhat counter-intuitively, as residents progress through their training, they become less comfortable with administering pain medication to a dying child fearing the pain medication may hasten death. The authors postulate that in the early years residents may have an intellectual grasp of pain control, but with time, having to assume more direct responsibility for pain relief may raise concerns about hastening death. This important, though worrying finding, with its potential for undertreatment of pain, underscores the urgency of addressing factual and ethical concerns relating to use of analgesia and sedation in dying children. The longitudinal nature of this study adds useful insights into the socialisation of young paediatricians as they learn to master stressful issues around end of life care.

Although surveyed paediatric oncologists[85] were inclined to dismiss formal training in end of life care, the research team nonetheless concluded that respondents had minimal actual experience of such programmes, which should encompass current palliative care and hospice rotations during specialty training and on continuing medical education classes.

In light of these surveys, a timely article[119] presents recommendations for improving education of physicians about end of life care in paediatric settings. The authors, from a variety of professional backgrounds and institutional settings, constituted a Working Group on End of Life Care in Pediatric Settings. This was 1 of 8 working groups convened at the National Consensus Conference on Medical Education for Care Near the End of Life that met in Washington, D.C. in 1997. The authors identified key educational issues in children's end of life care and offered instructional strategies tailored to address each issue. These include effective communication, management of pain and other symptoms, unique ethical problems in paediatric end of life care, and personal and professional challenges faced by providers of end of life care. Consistent with residents' self-reports[118] that they learn more through direct interaction with families of dying children, the working group stress that effective teaching about death and dying does not require the invention of a new curriculum. Instead, they suggest systematic and explicit instruction, which capitalises on teachable moments occurring around students' daily activities. According to the working group, the ultimate goals of instruction in end of life care are more humane care for very sick children, better bereavement outcomes for survivors and development of more confident clinicians. Notably, the Working Group contends that most of these issues transcend patient age, and can be used to inform medical education about the care of any terminally ill patient.

In summary, there is a growing body of data describing end of life care for neonates and children who die in acute hospital settings. With the development of new technologies, medicine is now able to keep terminally ill patients alive for longer periods without curing or ameliorating the underlying condition. If life-sustaining therapies such as ventilation and artificial nutrition and hydration are used to prolong dying, these interventions become a double-edged sword. Medical treatment that extends life may result in patients spending their final days and weeks unable to eat, drink or breathe without the assistance of feeding tubes, IV lines or ventilators. Empirical studies show that at the end of life terminally ill children, confined to hospitals and intensive care units, often die in considerable pain and discomfort. Whilst studies show that the practice of withholding and withdrawing life-sustaining therapies occurs commonly in hospitals, many issues remain unresolved, such as whether it is ever appropriate to withdraw artificial nutrition and hydration from dying children. When a terminally ill infant with HIV/AIDS is admitted to hospital with an acute episode of pneumonia or diarrhoea, should treatment aim to cure the underlying opportunistic infection or should the goal of treatment be palliation? Studies of children with cancer and CF show clinicians rarely opt for full palliation, instead they choose mixed management strategies which include aggressive care as well as relief of pain and suffering.

In SA, the number of children with HIV/AIDS dying in hospitals is increasing rapidly. Given scarce human and physical resources, doctors face agonising decisions regarding the kind of treatment these children ought to receive. Currently there are no empirical data on end of life practices for HIV-infected children to inform practice. The present study examined end of life decision making in a sample of HIV-infected children who died in hospital to gather baseline data for recommendations for appropriate terminal care. Its results are described in the following chapter.

Chapter 3: Results

3.1 Sample Characteristics

One hundred and sixty five (99%) out of 167 eligible patients were included in the final sample. Two patients were excluded because 1 folder could not be traced and 1 set of medical notes was missing. Seventy nine percent and 21% respectively of patients died in general wards and the paediatric intensive care unit (PICU). Demographic and clinical characteristics of the sample are shown in Table 2.

Table 2
Frequency and Percentage Distribution of Patients' Demographic and Clinical Characteristics (N=165)

	N	%	Mean	SD	Range	25%ile	Median	75%ile
Gender								
Male	83	50%						
Female	82	50%						
Race*								
Black	156	95%						
Coloured	9	5%						
Age (months)	**165**		**10**	**16.35**	**1-111**	**3**	**4**	**9**
0-6	111	67%	3				3	
7-12	22	13%	9				9	
13-24	17	10%	18				17	
25+	15	9%	51				36	
Length of Stay (days)	**165**		**11**	**12.94**	**1-88**	**3**	**6**	**13**
0-3	42	26%	2				2	
4-6	45	27%	5				5	
7-15	40	24%	10				9	
16+	38	23%	28.5				25.5	
Severity								
Category A	1	1%						
Category B	50	30%						
Category C	114	69%						

*Proxy measure for language

The sample was equally divided between male and female patients, most (95%) of whom were black. The overall average and median age of patients was 10 and 4 months respectively. Eighty percent of patients were under 1 year of age. Less than 10% of patients were older than 2 years (age category 25+ months). The mean and median age of this latter group of patients was 51 and 36 months respectively. This was decidedly higher than both the overall mean and median age, and the mean and median age of the nearest age category (13-24 months). Over two thirds of patients fell into Category C, the severest disease category. Only 1 patient fell in Category A (age: 1 month, length of stay: 5 days).

The mean and median length of terminal hospitalisation for all patients was 11 and 6 days respectively. The length of stay for 75% of patients was less than 2 weeks. One quarter of patients survived on average only 2 days. In contrast, 23% of patients had average lengths of stay of almost 1 month. The median length of stay (25.5 days) for these patients was more than four-fold longer than the overall median length of stay. Included in this group were 2 patients with terminal hospitalisations of well over 2 months (2.6 months and 2.9 months).

Patients with shorter mean and median lengths of stay were significantly more likely to fall into Category B. (Table 3) Moreover, the average length of stay of patients in Category C was twice

that of patients in Category B, respectively 13 and 6 days (P=0.0000). Sixty eight percent (34/50) of patients in Category B compared with 46% (53/114) of patients in Category C had lengths of stay less than 1 week. Only 4 (11%) patients in Category B compared to 33 (89%) patients in Category C fell in the longest length of stay quartile (≥16 days). Indeed this inverse trend was repeated in all length of stay quartiles classified according to disease severity: whereas the proportion of patients in Category B decreased with increasing length of stay, correspondingly the proportion of patients in Category C increased with longer length of stay (P=0.0056).

Table 3
Associations between Severity, Length of Stay and Age[a]

Severity and Length of Stay

Severity[b]	Length of Stay (days)					
	0-3 N=42 N (%)	4-6 N=45 N (%)	7-15 N=40 N (%)	16+ N=37 N (%)	χ^2	P-value
Category B N=50	20 (48%)	14 (31%)	12 (30%)	4 (11%)	12.59	0.0056
Category C N=114	22 (52%)	31 (68%)	28 (70%)	33 (89%)		

	Mean Length of Stay (days) according to Disease Severity					
Severity	N	Mean	SD	Median	χ^2[c]	P-value
Category B	50	6	5.71	4	13.84	0.0000
Category C	114	13	4.53	7		

Severity and Age

Severity	Age (months)					
	0-6 N=110 N (%)	7-12 N=22 N (%)	13-24 N=17 N (%)	25+ N=15 N (%)	χ^2	P-value
Category B	42 (38%)	5 (23%)	3 (18%)	0 (0%)	11.17	0.0180
Category C	68 (62%)	17 (77%)	14 (12%)	15 (100%)		

	Mean Age (months) according to Disease Severity					
	N	Mean	SD	Median	χ^2[c]	P-value
Category B	50	4	2.97	3	20.18	0.0000
Category C	114	12.5	19.50	5		

Length of Stay and Age

	Mean Age (months) according to Length of Stay Category					
Length of Stay	N	Mean	SD	Median	χ^2[c]	P-value
0-3	42	9	11.53	4.5	4.55	0.2078
4-6	45	13	21.85	4		
7-15	40	7	8.02	4		
16+	38	12	19.44	6		

	Mean Length of Stay (days) according to Age Category					
Age	N	Mean	SD	Median	χ^2[c]	P-value
0-6	111	10	9.69	6	1.484	0.6858
7-12	22	11	17.23	5		
13-24	17	17	22.57	7		
25+	9.2	9	10.53	6		

[a] In this Table length of stay and age are treated as categorical and ordinal variables.
[b] Analyses exclude 1 patient from Category A.
[c] Kruskall-Wallis H (equivalent chi square).

On average, patients in Category C were also significantly older than patients in Category B, 12.5 and 4 months respectively (P=0.0000). In comparison, age was not statistically associated with length of stay. (Table 3) In 3 length of stay categories, the median age was approximately 4 months, in keeping with the overall median age. Similarly, mean and median lengths of stay were not significantly different for any age group and in 2 age groups the median length of stay resembled the overall median length of stay of 6 days.

3.2 End of Life Decisions and Life-sustaining Interventions

3.2.1 Do Not Resuscitate Orders

Most (84%) patients had a DNR order. (Table 4)

Table 4
DNR Orders: Frequency, Percentage Distribution and General Characteristics

Do Not Resuscitate Orders	**138**	**84%**
Location of DNR Order		
Medical and Nursing Notes	57	41%
Medical Notes only	77	56%
Nursing Notes only	4	3%
Location in Doctors' Notes:		
In medical notes	115	83%
In front of medical notes	78	57%
Documented Rationale for DNR orders	85	61%
DNR order discussed with:		
Mother	36	26%
Mother & Father	14	10%
Aunt	1	0.7%
No record	87	63%

"Not for IPPV" was the most common instruction in DNR orders, either as a sole directive (N=56, 42%) or in combination with other do not resuscitate measures, comfort care plans or orders to withhold life-sustaining interventions (N=48, 36%). (Table 5 - following page) Not for active resuscitation, CPR or Red Box was the first line of instruction in 20% 0f DNR orders. A comprehensive, non-specific order to withhold active treatment, intervention or management was uncommon, constituting only 2% of DNR orders. Less than two thirds of DNR orders had a documented rationale. (Table 4) Advanced, progressive disease, and end stage, terminal or Category C disease were the most common reasons for writing a DNR order. (Table 6) Futility

Table 6
Thematic Categorisation of Rationales for DNR orders (Frequency Distribution N=85))

	No.
Severe disease with progressive symptomatology:	41
Advanced AIDS with progressive disease despite full treatment	
HIV+ve with progressive disease	
RVD with pneumonia	
Clinical AIDS	
No improvement and deterioration	11
Terminal illness	10
Poor Prognosis	8
End stage	6
Category C disease	5
Futility	2
Moribund	1
Brain death	1

Table 5
Frequency Distribution of Verbatim DNR Orders[a] (N=134)

No.	Verbatim DNR Order
56	Not for IPPV
15	Not for IPPV or active resuscitation
2	Not for IPPV or Red Box
2	Not for IPPV. Full ward treatment.
2	Not for ICU.
2	Not for re-intubation if arrests.
1	Not for IPPV. Not a good candidate for ICU. Not for Red Box.
1	Not for IPPV, ICU or intubation
1	Not for IPPV. No heroics.
1	Not for IPPV, ventilation or bagging.
1	Not for assisted ventilation.
1	Not for assisted ventilation. Keep comfortable.
1	Not for IPPV. Continue supportive care.
1	Not for IPPV, on maximal therapy.
1	Not for IPPV. Continue Bactrim and HBO_2.
1	Not for IPPV. Continue antibiotics, no invasive investigations.
1	Not for IPPV. Continue full ward treatment.
1	Not for IPPV. Continue with fluids and IV antibiotics.
1	Not for IPPV. No invasive investigations or IV medications.
1	Not for IPPV. Not for ICU or dopamine.
1	Not for IPPV. Not for active resuscitation. No procedures or IVs.
1	Not for IPPV. Not for invasive investigations or IV therapy.
1	Not for IPPV. Not for repeat bloods.
1	Not for IPPV. Full conservative care.
1	Not for IPPV. Supportive care only. No drips.
1	Not for IPPV. Continue TPN. No blood products.
1	Not for IPPV or active resuscitation. Only give platelets if bleeds.
1	Not for IPPV or dopamine if deterioration.
1	Not for IPPV, CPR or ICU admission. Full supportive care.
1	Maximum support short of IPPV.
8	Not for active resuscitation.
8	Not for CPR in event of arrest.
2	Not for Red Box.
2	Not for CPR or prolonged bagging or adrenaline.
1	Not for active resuscitation or ICU.
1	Not for extraordinary resuscitation measures.
1	Not for persistent resuscitation.
1	Not for CPR or drugs.
1	Not for CPR or adrenaline.
1	Not for CPR. Continue IPPV[b].
1	Not for CPR or bagging.
2	Not for active treatment.
1	Not for active intervention if patient has a cardiac arrest.
1	Not for active management.

[a] Categorised according to nature of first intervention noted in DNR to be withheld: respectively ICU-based interventions, resuscitation and "active" treatment.
[b] Patient in PICU.

was offered as justification for the DNR order in only 2 patients. Verbatim rationales for DNR orders are fully reported in Appendix 2.

The DNR order appeared simultaneously in medical and nursing notes in approximately 40% of folders. (Table 4) In turn DNR orders were recorded in medical notes only, in 56% of folders and in nursing notes only, in 3% of folders. Doctors documented DNR orders in their clinical notes (83%), on the front page of the clinical notes (57%) or in both locations. (Table 4) About half (54%) the DNR orders appearing synchronously in medical and nursing notes were identical or equivalent. (Table 7)

Table 7
Matched Verbatim DNR Orders in Medical and Nursing Notes (N=57)

Medical Notes	Nursing Notes	Frequency
	Identical or Equivalent DNR Orders	
Not for IPPV	Not for IPPV	16
Not for CPR	Not for CPR	4
Not for ICU or re-intubation	Not for ICU or ventilation	3
Not for IPPV or resuscitation	Not for IPPV or resuscitation	2
Not for active resuscitation	Not for active resuscitation	2
Not for ambubagging or CPR	Not for ambubagging or CPR	1
Not for assisted ventilation	Not for assisted ventilation	1
Not for IPPV or Red Box	Not for IPPV or Red Box	1
Not for Red Box	Not for Red Box	1
	Sub Total	**31**
	Discrepant DNR Orders	
Not for IPPV	Not for active resuscitation	9
Not for active resuscitation	Not for IPPV	3
Not for IPPV or active resuscitation	Not for IPPV	2
Not for CPR[a]	Not for active resuscitation	2
Not for IPPV, ICU or CPR	Not for IPPV	1
Not for IPPV or active resuscitation	Not for active management	1
Not for IPPV	Not for active resuscitation or ICU	1
Not for Red Box [a]	Not for resuscitation	1
Not for active resuscitation or Red Box [a]	Not for Red Box	1
Not for CPR, prolonged bagging or adrenaline	Not for active treatment	1
Not for persistent resuscitation [a]	Not to continue ambubagging	1
Not for adrenaline, inotropes or resuscitation	Not for active treatment	1
Not for IPPV, bagging or ventilation	Not for Red Box	1
Not for active management	Not for Red Box	1
	Sub Total	**26**

[a] If Not for Red Box, CPR, ambubagging, and active resuscitation are equivalent instructions then these DNR orders are similar in intent, if not language.

In contrast, discrepant orders for the same patient occurred in over 2 in 5 folders. Typically, directives such as "Not for active resuscitation", "Not for CPR" and "Not for Red Box" were used interchangeably and inconsistently in medical and nursing notes.

In almost two thirds of folders there was no record of whether the DNR order had been discussed with parents or a caretaker. (Table 4) DNR-related shortcomings with the potential to lead to miscommunication and misunderstanding within the health team and between parents and the health team are summarised in Table 8. Of note, this Table is based on some findings still to be presented in the following sections.

Table 8
Summary Distribution of Actual and Potential DNR-related Miscommunication and Misunderstanding

Communication Problems	Frequency	%
DNR orders with no documented discussion with parents or caretakers	87/ 138	63%
DNR orders with no comfort care plans	69/ 138	50%
DNR orders with no documented rationale	53/ 138	38%
Doctors referred to DNR from *previous* admission as a standing order	8/ 138	6%
Date missing from DNR order in front of folder (and no DNR inside medical notes)	2/ 138	1%
Junior doctors plead for clarification of DNR status of dying patient	2/ 165	1%
Documented evidence of dying but no DNR order	5/ 83	6%
Documented CCP but no DNR order	4/ 73	5%
DNR orders in medical notes only	77/ 138	56%
DNR orders in nursing notes only	4/ 138	3%
Discrepant DNR orders in medical and nursing notes[a]	26/ 57	46%
CPR despite DNR orders	7/ 41	17%

[a] Interchangeable and inconsistent use of DNR instructions, in particular terminology.

3.2.2 Evidence of Dying and Comfort Care Plans

One in 2 patients was identified as dying and 2 in 5 patients had a documented comfort care plan. (Table 9)

Table 9
Frequency and Percentage Distribution of Selected End of Life Decisions

Identified as Dying	**83**	**50%**
Comfort Care Plan	**73**	**44%**
Comfort care plan discussed with:		
Mother	31	43%
Mother and Father	9	12%
Aunt	1	1%
No record	32	44%
Withdrawing Treatment	**21**	**13%**
Withholding Treatment	**19**	**11.5%**

One third of patients (N=52) had both evidence of dying and a comfort care plan in their folders. Most patients with evidence of dying or with a comfort care plan had a DNR order (N=77, 93% and N=69, 94% respectively). Comfort care plans were discussed with 56% of parents or caretakers. (Table 9). It is noteworthy that doctors were significantly more likely to discuss comfort care plans than DNR orders with guardians (56% versus 36%; P=0.0083).

Verbatim evidence of dying and verbatim comfort care plans are fully outlined in Appendices 3 and 4.

Among patients identified as dying, approximately 2 in every 3 were noted to be terminally ill or end stage, 1 in 3 was said to have a poor prognosis and the condition of 1 in 20 patients was felt to be rapidly deteriorating, with a low likelihood of improvement. (Table 10)

Table 10
Thematic Categorisation of Evidence of Dying (N=83)

Categorisation	Frequency
Terminal illness/ dying	36
Poor prognosis	29
End Stage/ In extremis	14
Deterioration/ no improvement	4

Comfort care plans were roughly categorised according to their main directives. (Table 11)

Table 11
Thematic Categorisation of Verbatim Comfort Care Plans (N=73)

Categorisation	Frequency
TLC	30
Keep comfortable	15
Supportive care	14
Palliation and analgesia	8
Terminal care	2
Not for aggressive investigation or painful procedures	2
Conservative management	1
Withdraw curative care	1

Tender Loving Care (TLC) formed the basis of 2 in every 5 plans and keeping patients comfortable and providing supportive care respectively underlined a further 1 in 5 plans. Palliation and analgesia were the stimulus for 1 in 10 plans and a general directive to manage conservatively and forgo further aggressive interventions and painful procedures underpinned the remaining 5% of plans. However, there was much overlap between these categories, for example 'palliation' might have included TLC+++ or, conversely, TLC might have included palliation. In addition to these general instructions, two thirds of comfort care plans incorporated specific directives to either withhold or withdraw selected interventions, such as invasive procedures, blood products or intravenous (IV) therapies, or to add therapies, for example, morphine, sedation or headbox oxygen (HBO_2), to current treatment regimens. Four (5%) comfort care plans recommended transfer to a side cubicle. A further 4 plans specified the withdrawal of curative care of which only 1 plan included the directive to change *goals* of treatment.

3.2.3 Withdrawing and Withholding Treatment

Treatment was withdrawn or withheld from 13% and 11.5% of patients respectively. (Table 9) As already mentioned, doctors' orders to withdraw or withhold an intervention generally accompanied a DNR order or comfort care plan. (Table 5 and Appendix 4)

The most frequent interventions to be withdrawn and withheld were ventilation, blood products and IV antibiotics. (Table 12)

Table 12
Frequency Distribution of Decisions to Withdraw and Withhold Interventions

Interventions	Frequency
Ventilation	13
Blood products	7
IV antibiotics	5
IV fluids	3
HBO_2	3
Oral antibiotics	2
All curative care	2
Oral feeds	1
NPO_2	1
Surgery	1
TPN	1
Renal dialysis	1

In 3 instances, drips for IV antibiotic therapy tissued and were not re-sited. Likewise, a chest drain was not re-inserted when it disconnected from the patient. Major invasive interventions, namely TPN, renal dialysis and surgery, were withheld from 3 patients. In 1 case a mother insisted that HBO_2 be withdrawn from her 4-month-old son. According to the final entry in the nursing notes, the infant died quickly with no documented respiratory distress. Prior to treatment withdrawal, the paediatric consultant-on-call insisted the mother sign informed consent for the withdrawal, although the doctor's assessment indicated that 'death is inevitable in the short-term'. The patient died in his mother's arms. The average length of survival following treatment withdrawal was 0.7 days, with 86% (N=18) of patients dying almost immediately. In contrast, patients lived on average 5 days (median 4 days) after a decision to withhold treatment.

3.2.4 Paediatric Intensive Care and Cardiopulmonary Resuscitation

Thirty eight patients (23%) were admitted to the paediatric intensive care unit (PICU) during their terminal hospitalisation of whom almost half (N=18) were transferred from general wards in RXH. Severe respiratory disease accounted for 76% (29/38) of admissions to the PICU. The HIV status of 10 (26%) patients was known prior to admission to the PICU. Thirty four patients died in the PICU. Six patients were transferred out of the PICU and died in the general wards. Compared to patients in the general wards, patients in the PICU were significantly less likely to have a documented DNR order (68% versus 89%; $\chi 2 = 9.11$, P=0.0025) and comfort care plan (29% versus 49%; $\chi 2 = 4.56$, P=0.0359). Fifty percent of patients in the PICU were identified as dying.

Treatment was significantly more likely to be withdrawn in the PICU compared with the general wards (38% versus 6%; $\chi 2 = 23.7$, P=0.0000). Approximately 1 in 3 (N=13) patients was extubated and removed from the ventilator prior to death. Consensus regarding extubation was reached between all parents (mothers and fathers where possible) and the health care team.

One in 4 patients received cardiopulmonary resuscitation (CPR) during his or her terminal hospitalisation of whom half were resuscitated in a general ward. (Table 13) When

administered in patients' last 24 hours of life, CPR was significantly more likely to be performed in the PICU (38% versus 8%; $\chi 2 = 21.4$, P=0.0000).

Table 13
Cardiopulmonary Resuscitation: Frequency and Percentage Distribution and General Characteristics

	N	%			
CPR	41	25%			
Ward administered:					
emergency	3	7%			
general	21	51%			
PICU	17	41%			
HIV status confirmed prior to CPR					
yes	13	32%			
no	28	68%			
CPR in presence of:					
Evidence of dying					
yes	5 /83	6%		$\chi 2 = 9.70$	**P-value = 0.0018**
no	19 /82	23%			
Comfort Care Plan					
yes	10 /73	14%		$\chi 2 = 8.66$	**P-value = 0.0032**
no	31 /92	34%			
No specified orders					
yes	10 /20	50%		$\chi 2 = 22.88$	**P-value = 0.0000**
no	14 /145	10%			
CPR *in last 24 hours*					
general ward	11 /131	8%		$\chi 2 = 19.32$	**P-value = 0.0000**
PICU	13 /34	38%			
Outcome of CPR					
failed	20 /41	49% (6 patients survived < 1 day)			
CPR to death (days)	**Mean**	**SD**	**Median**	**Range**	
	1.5	4.4	0	0-27	

The HIV status of 1 in 3 patients was known prior to CPR. CPR was unsuccessful in almost 50% of patients, with median survival less than 1 day. Average length of survival following CPR was less than 2 days. CPR was performed on 7 patients despite their having a DNR order. Patients identified as dying and patients with a comfort care plan, were significantly less likely to have CPR (P=0.0018 and P=0.0032 respectively). (Table 13) Still, 5 patients with evidence of dying and 10 patients with a comfort care plan received CPR following an arrest. One in 2 patients (10/20) with no DNR, evidence of dying or comfort care plan, compared with 1 in 10 patients with some end of life decision, received CPR (P=0.0000). (Table 13)

3.2.5 Morphine Administration

The frequency and general characteristics of morphine administration are shown in Table 14. Two in 5 patients, including those in the PICU, received morphine during their terminal admission. Slightly fewer patients (38%) received morphine in their last 24 hours of life. Patients who died in the PICU had a 2-fold better chance of receiving morphine shortly before death than patients who died in general wards (68% versus 30%, P=0.0000). Forty one percent of patients were given oral morphine, of whom almost half received only 1 dose during their hospitalisation. Of patients on oral morphine, only 5 (13%) received 10 or more doses of morphine during their terminal stay in hospital. On average, patients in a general ward were hospitalised for more than 2 weeks before they received their first dose of morphine. This was 3 times longer than patients admitted to the PICU (P=0.0004). Moreover, the duration of morphine administration was markedly shorter in general wards. On average, these patients received morphine for 2 days, with a median length of administration of 1 day or less.

Table 14
Morphine Administration: Frequency and Percentage Distribution and General Characteristics

Morphine	68	41%		
In *last 24 hours*	63	38%		
Ward				
General	40 /131	30%	$\chi 2$ 15.66	**P = 0.0000**
PICU	23 /34	68%		
Dosage				
Continuous	30	44%		
6 hourly	15	22%		
4 hourly	12	18%		
Bolus	7	10%		
12 hourly	2	3%		
PRN	2	3%		

Frequency of Oral Doses *(per patient)*

Number of Doses	**N=37**
1	17
2	2
3	2
4	1
5	2
6	6
9	2
10	1
11	1
15	1
16	1
28	1

Admission to Morphine Administration (days)

Ward	**N**	**Mean**	**SD**	**Range**	**Median**	
General	45	15	18.70	0-80	6	$\chi 2$ 12 .38 **P = 0.0004**
PICU	23	5	7.97	0-28	0	

Morphine Administration to Death (days)

Ward	**N**	**Mean**	**SD**	**Range**	**Median**	
General	45	2	3.10	0-19	1	$\chi 2$ 17.24 **P = 0.0000**
PICU	23	6	5.56	0-20	4	

3.2.6 Social Work and Spiritual Intervention

Social work intervention took place in approximately 2 in every 5 families. (Table 15)

Table 15
Social Work Intervention: Frequency and Percentage Distribution and General Characteristics

Social Work Intervention	63	38%
Number of Visits (per patient)		
1	44	70%
2	13	21%
>3	6	9%
Reason for Social Work Intervention		
Supportive counselling	18	29%
Post-test counselling	14	22%
Grief counselling	14	22%
Pre & post test counselling	9	14%
Pre-test counselling	8	13%

Families typically received 1 visit during a patient's terminal hospitalisation, with less than 10% seen by a social worker on more than 3 occasions. Supportive counselling was the most common reason for social work involvement in about one third of families, followed by grief counselling and post-test counselling. It is noteworthy that some form of pre- or post- test counselling accounted for about half the social work interventions. The only 2 documented referrals to community services included the Red Cross Society and the South African Police Service (where a patient had suffered non-accidental injury prior to admission to RXH).

On parental request, clergy were present at the death of 3 patients. In 1 instance, the priest baptised the dying infant in the PICU, shortly before extubation.

3.2.7 Associations between End of Life Decisions and Length of Stay, Age and Severity

Significant and non-significant associations between DNR orders, evidence of dying, comfort care plans, withdrawing and withholding treatment and the independent variables of length of stay, age and severity are shown in Table 16. Age as a categorical variable was not significantly associated with end of life decision making. As a categorical variable, length of stay was significantly associated with comfort care plans (P=0.0081), and withdrawing and withholding treatment (P=0.0323 and P=0.0093 respectively). Almost twice as many patients in the longest length of stay quartile (16+ days) had comfort care plans compared to patients with lengths of stay less than 1 week. Similarly, patients with lengths of stay ≥16 days had a 1 in 4 chance of having treatment withheld compared to a less than 1 in 10 chance for the remaining patients, regardless of their length of stay. In contrast, patients with lengths of stay between 4 and 15 days were at least 3 times more likely to have treatment withdrawn than patients with lengths of stay less than 3 days or greater than 16 days. Severity was significantly associated with evidence of dying (P=0.0049) and having a comfort care plan (P=0.0135). Approximately 60% of patients who were identified as dying fell in Category C compared to 34% of patients in Category B. By the same token, 1 in 2 patients with a comfort care plan fell in Category C compared to less than 1 in 3 patients in Category B. Surprisingly, severity was not significantly associated with issuing a DNR order or administering CPR. Seventeen (34%) patients in Category B and 24 (21%) patients in Category C had CPR during their terminal hospitalisation ($\chi 2 = 0.94$, P=0.3331). Nor was severity significantly associated with admission to the PICU. Twenty eight percent of patients in Category B and 21% of patients in Category C were admitted to the PICU ($\chi 2 = 0.94$; P=0.3331).

Statistical relationships were also examined between end of life decisions and age and length of stay as continuous variables. (Table 17) Whereas age as a categorical variable showed no statistically significant association with key end of life decisions, highly significant differences were found between mean age and documentation of a comfort care plan (P=0.0052) and documentation of *both* evidence of dying and a comfort care plan (P=0.0004). In both sets of associations, the mean age of patients with these decisions (14 months and 16 months respectively) was at least twice that of patients with no comfort care plan and evidence of dying (7 months). Likewise, the median ages differed by at least 2 months (6 months and 6.5 months versus 4 months). In contrast, patients who were admitted to the PICU or who received CPR were on average significantly younger than patients who did not receive these interventions (P=0.0101 and P=0.0179 respectively). There was no statistically significant relationship between age and patients with no documented end of life decisions. Both sets of patients had median lengths of stay of 4 days ($\chi 2 = 0.000$, P=0.9939).

Table 16
End of Life Decisions According to Categories of Length of Stay, Age and Severity

Do Not Resuscitate Orders

Length of Stay

Days	N	%	Total
0-3	32	76%	42
4-6	35	78%	45
7-15	37	93%	40
16+	34	89%	38
	138		

$\chi 2 = 6.07$
P = 0.1081

Age

Months	N	%	Total
0-3	94	85%	110
4-6	19	83%	23
12-24	14	82%	17
25+	11	73%	15
	138		

$\chi 2 = 1.47$
P = 0.6898

Severity

Severity	N	%	Total
Cat B	41	82%	50
Cat C	97	85%	114
	138		

$\chi 2 = 0.25$
P = 0.7900

Evidence of Dying

Length of Stay

Days	N	%	Total
0-3	17	40%	42
4-6	21	47%	45
7-17	21	52%	40
16+	24	63%	38
	83		

$\chi 2 = 4.5$
P = 0.2168

Age

Months	N	%	Total
0-6	52	47%	110
7-12	13	56%	23
13-24	10	59%	17
25+	8	53%	15
	83		

$\chi 2 = 1.31$
P = 0.7270

Severity

Severity	N	%	Total
Cat B	17	34%	50
Cat C	66	58%	114
	83		

$\chi 2 = 7.94$
P = 0.0049

Comfort Care Plans

Length of Stay

Days	N	%	Total
0-3	14	33%	42
4-6	14	31%	45
7-15	21	52%	40
16+	24	63%	38
	73		

$\chi 2 = 11.79$
P = 0.0081

Age

Months	N	%	Total
0-6	41	37%	110
7-12	13	56%	23
13-24	9	53%	17
25+	10	67%	15
	73		

$\chi 2 = 7.15$
P = 0.0672

Severity

Severity	N	%	Total
Cat B	15	30%	50
Cat C	58	51%	114
	73		

$\chi 2 = 6.13$
P = 0.0135

Withdrawing Treatment

Length of Stay

Days	N	%	Total
0-3	2	5%	42
4-6	8	18%	45
7-15	9	22%	40
16+	2	5%	38
	21		

$\chi 2 = 8.78$
P = 0.0323

Age

Months	N	%	Total
0-6	18	16%	110
7-12	2	9%	23
13-24	0	0%	17
25+	1	7%	15
	21		

$\chi 2 = 4.62$
P-= 0.2017

Severity

Severity	N	%	Total
Cat B	5	10%	50
Cat C	16	14%	114
	21		

$\chi 2 = 0.50$
P = 0.4778

Withholding Treatment

Length of Stay

Days	N	%	Total
0-3	2	5%	42
4-6	4	9%	45
7-15	3	7%	40
16+	10	26%	38
	19		

$\chi 2 = 11.49$
P = 0.0093

Age

Months	N	%	Total
0-6	12	11%	110
7-12	3	13%	23
13-24	2	12%	17
25+	2	13%	15
	19		

$\chi 2 = 0.30$
P = 0.9863

Severity

Severity	N	%	Total
Cat B	5	10%	50
Cat C	14	12%	114
	19		

$\chi 2 = 0.18$
P = 0.6753

Table 17
End of Life Decisions and Life-sustaining Interventions According to Mean and Median Age and Length of Stay

	Mean	SD	Median	χ^2	P-value
AGE (months)					
Study Sample (N = 165)	**10**	**16.55**	**4**		
DNR order					
Yes (N = 138)	10	17.02	4	0.018	0.8940
No (N = 27)	11	12.59	4		
Evidence					
Yes (N = 83)	12	20.29	5	2.896	0.0887
No (N = 82)	8	10.88	4		
Comfort Care Plan					
Yes (N = 73)	14	22.12	6	8.538	**0.0052**
No (N = 92)	7	8.47	4		
Evidence and Comfort Care Plan					
Yes (N = 52)	16	24.58	6.5	12.30	**0.0004**
No (N = 113)	7	9.66	4		
Withdrawing Treatment					
Yes (N = 21)	5	6.27	4	2.057	0.1514
No (N = 144)	11	13.54	4		
Withholding Treatment					
Yes (N = 19)	11	14.30	5	1.028	0.3106
No (N = 146)	10	16.64	4		
PICU					
Yes (N=38)	7	11.05	4	5.599	**0.0170**
No (N=127)	11	17.56	5		
CPR					
Yes (N=41)	8	12.61	3	6.603	**0.0101**
No (N=124)	11	17.40	5		
LENGTH of STAY (days)					
Study Sample (N=165)	**11**	**12.94**	**6**		
DNR order					
Yes (N = 138)	12	13.67	7	3.845	**0.0499**
No (N = 27)	7	7.33	5		
Evidence					
Yes (N = 83)	13	15.35	7	5.017	**0.0250**
No (N = 82)	9	9.54	5		
Comfort Care Plan					
Yes (N = 73)	14	14.35	9	11.54	**0.0006**
No (N = 92)	8	11.13	5		
Evidence *and* Comfort Care Plan					
Yes (N = 52)	14	14.47	8.5	6.802	**0.0091**
No (N = 113)	9	11.87	5		
Withdrawing Treatment					
Yes (N = 21)	9	7.75	6	0.139	0.7094
No (N = 144)	11	13.54	7		
Withholding Treatment					
Yes (N = 19)	24	25.31	16	8.171	**0.0042**
No (N = 146)	9	9.13	6		
PICU					
Yes (N=38)	8.5	8.39	6	0.842	0.3586
No (N=127)	11.5	13.90	6.5		
CPR					
Yes (N=41)	7	7.95	5	6.96	**0.0083**
No (N=125)	12	13.94	6		

As a continuous variable, length of stay was significantly associated with having a DNR order (P=0.0499), evidence of dying (P=0.0250), having a comfort care plan (P=0.0006), evidence of dying *and* having a comfort care plan (P=0.0091) and withholding treatment (P=0.0043). On average patients with these end of life decisions had lengths of stay at least 5 to 6 days longer than patients without an end of life decision. The median length of stay of patients with these decisions was at least 1 week. Patients from whom treatment was withheld had a median length of stay of over 2 weeks (16 days) compared with a median length of stay of less than 1 week for patients who did not have treatment withheld. Whilst the mean and median length of stay were not significantly different for patients admitted to the PICU, patients who were resuscitated had significantly shorter (on average 5 days) terminal hospitalisations (P=0.0083). Although there was a tendency for patients with no end of life decisions to have shorter lengths of stay (mean lengths of stay of 6 versus 13 days and median lengths of stay of 4.5 versus 6 days), this association was not statistically significant ($\chi 2 = 3.27$, P=0.0818).

3.2.8 Timing of End of Life Decisions

As indicated by the median length of time from admission to end of life decision points shown in Table 18, there is a progression from DNR orders (4 days) to identifying a patient as dying (5 days) to documenting a comfort care plan (7 days).

Table 18
Timing and Sequence of End of Life Decisions (days)

	Mean	SD	Range	Median
Admission to DNR [a]	7	10.78	0-71	4
Admission to identified as dying [b]	9	12.38	0-83	5
Admission to comfort care plan [c]	10	12.09	0-61	7
Identified as dying to comfort care plan [d]	2.5	9.39	0-64	0
DNR to death [a]	5	6.74	0-34	2
Identified as dying to death [b]	4	8.88	0-65	2
Comfort care plan to death [c]	4	5.29	0-33	2

[a] N=136 (dates missing for 2 DNR orders), [b] N=83, [c] N=73, [d] N=49

Once an end of life decision has been taken the median length of time to death was 2 days. For patients with evidence of dying and a comfort care plan, the median time between these decisions points was 0 days, suggesting that for at least half these patients the decisions were made simultaneously.

Table 19 confirms this sequence of end of life decisions for each length of stay category. However, for patients in the longest length of stay quartile (≥ 16 days), the average and median time between admission and writing a DNR order, evidence of dying and a comfort care plan increased almost 3 fold compared to patients with lengths of stay between 7 and 15 days. Average differences were in the order of 6 days versus 19 days for DNR orders, 8 days versus

26 days for identifying a patient as dying and 8 days versus 5 days for completing comfort care plans. In the shortest length of stay category (0-3 days), the mean and median time interval between writing a DNR order, identifying a patient as dying and documenting a comfort care plan was less than 1 day.

Table 19
Timing of End of Life Decisions According to Length of Stay (days)

	Admission to DNR			Admission to identified as dying			Admission to Comfort Care Plan		
Length of stay	N	Mean	Median	N	Mean	Median	N	Mean	Med
0-3	32	0.8	0	17	0.6	0	14	0.7	0.5
4-6	35	4	3	21	3	3	14	3	4
7-15	36	6	6	21	8	7	21	8	7
16+	33	19	17	24	26	23	24	25	23.5
	136			83			73		
	$\chi 2 = 56.84$ P = 0.0000			$\chi 2 = 57.56$ P = 0.0000			$\chi 2 = 46.70$ P = 0.0000		

All associations between length of stay categories and end of life decision points reached high levels of statistical significance (Table 19).

Severity was not statistically associated with the timing and sequence of end of life decisions (Table 20).

Table 20
Timing of End of Life Decisions According to Severity

	Admission to DNR			Admission to identified as dying			Admission to Comfort Care Plan		
Severity	N	Mean	Median	N	Mean	Median	N	Mean	Med
Cat B	41	3.5	2	17	6	4	15	6	4
Cat C	95	8	5	66	10	6	58	11.5	7
	136			83			73		
	$\chi 2 = 2.837$ P = 0.0921			$\chi 2 = 0.358$ P = 0.5498			$\chi 2 = 0.568$ P = 0.4511		

Since no statistically significant associations were found between age as a categorical variable and end of life decisions (Table 16), no further analyses were undertaken to examine end of life decision points and age categories.

3.3 Interventions in the Last 24 Hours of Life

The frequency of interventions in patients' last 24 hours of life is shown in Table 21.

Table 21
Frequency Distribution of Interventions in the Last 24 Hours of Life (N=165)

	N	%
IV fluids	133	81%
IV antibiotics	122	75%
N-G feeds	99	60%
Nystatin	88	53%
HBO_2	68	41%
Morphine	63	38%
Panado	51	31%
Oral antibiotics	44	27%
NPO_2	45	27%
Venipuncture	40	24%
Steroids	35	21%
Nebulisation	31	19%
Ventilation	29	18%
Sedation	28	17%
X-rays	27	16%
CPR	24	14%
Ringers lactate	24	14%
Inotropes	21	13%
Oral feeds	20	12%
N-G drainage tube	19	11%
Anticonvulsants	16	10%
Transfusion	15	9%
Physiotherapy	14	8%
Extubation	12	7%
A line	8	5%
CV line	8	5%
Intubation	7	4%
Muscle relaxants	7	4%
TPN	2	1%
Lumbar Puncture	1	1%
CT Scan	1	1%

IV fluids and IV antibiotics were the most common interventions administered to at least three quarters of patients in the final 24 hours of life. Other interventions received by at least 40% of patients included N-G feeds (3 in every 5 patients), Nystatin (1 in every 2 patients) and HBO_2 (2 in every 5 patients). Analgesia was the next most frequent end intervention with respectively 38% and 31% of patients receiving morphine and Panado. Approximately 1 in 4 patients received oral antibiotics and NPO_2 or had blood drawn in their final 24 hours of life, with a further 1 in 5 receiving steroids and nebulisation. A sizeable minority of patients was on ventilation or received CPR before death (18% and 14% respectively). Likewise, less than 15% of patients were treated with Ringers lactate and inotropes to sustain life (14% and 13% respectively). Only 1 in 10 patients was fed orally in the last 24 hours. Highly invasive procedures, shortly before death, such as intubation occurred in less than 5% of patients. On the other hand, almost twice as many patients were extubated. Similarly, the use of other intensive care-based interventions, such as A lines, CV lines and TPN, was uncommon. A CT scan was performed on 1 patient in the PICU to confirm brain death.

With the exception of TB medicines, administered to 7% of patients, additional interventions were used in less than 4% of patients. (Table 22)

Table 22
Frequency Distribution of Additional Interventions in Last 24 Hours of Life

	No.
T B medications	12
Betadine	7
Garlic	6
Lasix	3
Acyclovir	2
Sucralfate	2
Joules Solution	2
Catheterisation	1
Cimetidine	1
Chest Drain Insertion	1
Digoxin	1
ECHO	1
EEG	1
Flumazine	1
Lignocaine (for skin lesions)	1
Lung Scan	1
Maxalon	1
Naloxone	1
Stomach washout with charcoal	1

Several of these interventions, for example Betadine, sucralfate and Lignocaine, were aimed at the relief of pain caused by extensive oral and perianal ulceration. Invasive procedures, such as the insertion of a chest drain, occurred extremely rarely. An ECHO was performed in 1 patient who deteriorated rapidly and died soon after admission. A stomach washout was done in 1 patient with persistent vomiting, believed to have been caused by a toxic traditional medicine (the patient's HIV status was unconfirmed at the time). One patient received Naxolone to reverse an adverse reaction to morphine. A garlic derivative was prescribed for 6 patients with resistant oral candidiasis.

Mothers were present at the bedside in 30% (N=49) deaths. In 1 in 10 deaths both parents was present. Grandparents or other close relatives were present in less than 3% of deaths. As many as 75 (45%) patients died with no parents or relatives present. In 12% of deaths there was no record in the nursing or medical notes as to whether someone was present. According to entries in the nursing notes, mothers were at the bedside throughout the terminal hospitalisations of many patients (because these entries were erratic, accurate frequency data are not available). Breast-feeding was encouraged, and mothers were actively involved in the daily care of patients, which included washing, feeding and mouth and buttocks care. Nurses went to great lengths to contact parents immediately when patients showed signs of deterioration, often enlisting the assistance of the police service.

3.3.1 Associations between Interventions in the Last 24 Hours of Life and Age, Severity and Length of Stay

Associations between age and end interventions are shown in Table 23.

Table 23
Interventions in the Last 24 Hours of Life According to Mean and Median Age (months)

End Interventions	N	Mean[a]	SD	Median	$\chi 2$	P-value
IV fluids	**133**	**9 (13)**	**16.45**	**4 (6)**	**4.264**	**0.0389**
IV antibiotics	**122**	**8 (15)**	**14.15**	**4 (6)**	**9.142**	**0.0024**
N-G feeds	99	10 (10)	15.72	5 (4)	3.733	0.0533
Nystatin	88	9 (12)	10.69	4 (4)	0.141	0.7073
HBO_2	**68**	**5.5 (13)**	**5.25**	**3 (5)**	**9.831**	**0.0017**
Morphine	63	10 (10)	17.93	4 (4.5)	0.282	0.5955
Panado	51	10 (10)	12.45	4 (4)	0.194	0.6593
Oral antibiotics	**44**	**14.5 (8)**	**20.60**	**6 (4)**	**8.776**	**0.0030**
NPO_2	**45**	**15 (8)**	**21.81**	**7 (4)**	**12.00**	**0.0005**
Venipuncture	40	8 (11)	8.14	4 (4)	0.151	0.6593
Steroids	**35**	**8 (11)**	**16.19**	**3 (5)**	**8.782**	**0.0034**
Nebulisation	32	8 (10.5)	7.53	4 (4)	0.104	0.7474
Ventilation	**29**	**5 (11)**	**6.80**	**3 (5)**	**10.18**	**0.0014**
Sedation	**28**	**8 (10.5)**	**13.13**	**3 (5)**	**4.088**	**0.0431**
X-rays	27	7 (11)	7.02	4 (4)	0.059	0.8087
CPR	**24**	**7 (10.5)**	**11.38**	**3 (5)**	**5.043**	**0.0247**
Ringers lactate	24	10 (10)	12.4	4 (4)	0.019	0.8901
Inotropes	21	6 (11)	8.09	3 (4.5)	3.762	0.0524
Oral feeds	20	20 (7)	28.2	5.5 (4)	3.292	0.0696
N-G tube	19	4 (11)	2.75	3 (4)	3.616	0.0572
Anticonvulsants	16	14 (10)	21.70	4 (4)	0.000	1.0000
Transfusion	15	5 (10.5)	4.89	3 (4)	3.45	0.0628
Physiotherapy	14	13 (10)	29.25	4 (4)	1.674	0.1956
Extubation	12	3.5 (10)	1.50	3.5 (4)	3.58	0.0581
A line	8	6 (10)	5.19	4 (4)	0.041	0.8393
CV line	7	6 (10)	5.69	4 (4)	0.268	0.6047
Intubation	**7**	**4 (10)**	**5.77**	**2 (4)**	**7.588**	**0.0058**
Muscle relaxants	7	6 (10)	5.83	4 (4)	0.384	0.5356
TPN	2	4 (10)	1.41	4 (4)	0.190	0.6633
LP	1	6 (10)	0.00	6 (4)		
CT Scan	1					

[a] Mean and median age in brackets refers to patients *not* having the end intervention.

Mean and median age were significantly associated with use of IV fluids and IV antibiotics, HBO_2, and NPO_2, oral antibiotics, steroids, ventilation, sedation, CPR and intubation. On average, patients receiving IV therapies were between 6 and 7 months younger than patients

not receiving these therapies. The median age of patients on IV therapies was 4 months. Whereas patients receiving HBO_2 were on average more than half the age of patients not receiving the intervention (5.5 months versus 13 months; P=0.0017), patients who received NPO_2 were significantly older than patients not receiving this treatment (mean ages of 15 months and 8 months; P=0.0005). Oral antibiotics were administered to patients who on average were 6 months older than their counterparts who were not given oral antibiotics. Patients who were ventilated, sedated, intubated or received CPR were significantly younger than patients not given these interventions. The median ages of patients receiving ventilation, sedation and CPR were 3 months (versus 5 months) and patients who were intubated had a median age of 2 months (versus 4 months). Moreover, 90% (26/29) of patients who were ventilated in the last 24 hours were under 6 months. Patients who were treated with steroids were also significantly younger (on average, 8 months versus 11 months; P=0.0034).

Associations between interventions in the last 24 hours of life and length of stay are shown in Table 24. On average, patients who died whilst being treated with IV fluids and IV antibiotics had hospitalisations half the length of those not receiving IV therapies (respectively 9 days and 18 days; P=0.0023 and 8 days versus 20 days; P=0.0000). In contrast, patients who received oral antibiotics and N-G feeds had terminal stays on average twice the length of those not receiving these interventions (respectively 19 days versus 8 days; P=0.0002 and 14 days versus 6 days; P=0.0000). Only 1 in 5 patients with a length of stay of 3 days or less received oral antibiotics compared to 3 in 5 patients with a length of stay of 16 days or longer. Patients who received analgesia in their last 24 hours had significantly longer terminal stays. On average patients who received morphine had been in hospital 4 days longer than patients not receiving morphine (P=0.0172). Patients receiving either Panado or morphine had average terminal hospitalisations lasting a fortnight. The median length of stay for a patient receiving morphine was 1 week (compared to 5 days for those not receiving morphine). Diagnostic procedures such as drawing blood and X-rays in the last 24 hours were undertaken among patients with an average length of stay of 1 week or less, the median length of stay being only 3 days (P=0.0004 and P=0.0168 respectively). By the same token, life-sustaining interventions such as CPR, Ringers lactate and inotropes in the final 24 hours of life were significantly more likely to be administered to patients with average lengths of stay of 1 week or less (P=0.0380; P=0.0018 and P=0.0006 respectively). For example, two thirds of patients who received CPR in the last 24 hours had a length of stay 6 days or less. Blood transfusions at the end of life were also significantly more likely among patients with short terminal hospitalisations (a median length of stay of 2 days versus 6 days; P=0.0009). No patients with a length of stay greater than 16 days received a blood transfusion in their last 24 hours of life. Significant associations were also noted between length of stay and use of Nystatin and N-G tube drainage. Patients who received Nystatin had marginally longer lengths of stay (on average 12 days versus 10 days; P=0.0282), and those with N-G tube drainage had a shorter length of stay (on average 6 days versus 11 days; P=0.0277.

Significant associations between interventions in the last 24 hours and severity are highlighted in Table 25. IV antibiotics and N-G feeding were more likely in the last 24 hours among patients in Category B. Approximately 90% of patients in Category B compared to 68% of patients in Category C received IV antibiotics (P=0.0083). Conversely more than twice as many patients in Category C received oral antibiotics (31% versus 16%; P=0.0494). Likewise twice as many patients in Category C compared to Category B received morphine in the final

Table 24
Interventions in the Last 24 Hours of Life According to Mean and Median Length of Stay (days)

End Interventions	N	Mean[a]	SD	Median	$\chi 2$	P-value
IV fluids	**133**	**9 (18)**	**10.68**	**6 (14)**	**9.25**	**0.0023**
IV antibiotics	**122**	**8 (20)**	**7.16**	**5.5 (16)**	**20.27**	**0.0000**
N-G feeds	**99**	**14 (6)**	**14.68**	**8 (4)**	**28.65**	**0.0000**
Nystatin	**88**	**12 (10)**	**12.76**	**7 (5)**	**4.816**	**0.0282**
HBO_2	68	10 (11)	11.3	6 (6)	0.251	0.6161
Morphine	**63**	**13 (9)**	**14.58**	**7 (5)**	**5.670**	**0.0172**
Panado	**51**	**16 (9)**	**19.09**	**8 (6)**	**3.993**	**0.0455**
Oral antibiotics	**44**	**19 (8)**	**19.58**	**13.5 (5)**	**13.73**	**0.0002**
NPO_2	45	10 (11)	13.97	6 (6)	0.305	0.5808
Venipuncture	**40**	**6 (12)**	**6.69**	**3 (7)**	**12.27**	**0.0004**
Steroids	35	8 (11.5)	6.89	6 (6)	0.035	0.8509
Nebulisation	32	13.5 (10)	16.6	7 (6)	1.264	0.2609
Ventilation	29	7 (12)	5.58	5 (6)	3.144	0.0762
Sedation	28	7 (12)	5.82	5 (6)	1.904	0.1676
X-rays	**27**	**7 (12)**	**7.56**	**3 (6)**	**5.784**	**0.0168**
CPR	**24**	**7 (11.5)**	**6.35**	**5 (6)**	**4.302**	**0.0380**
Ringers lactate	**24**	**6 (12)**	**6.97**	**3 (7)**	**9.715**	**0.0018**
Inotropes	**21**	**5 (12)**	**5.57**	**3 (6.5)**	**11.74**	**0.0006**
Oral feeds	20	11 (11)	11.82	7 (6)	0.217	0.6414
N-G tube	**19**	**6 (11)**	**5.44**	**5 (6.5)**	**4.84**	**0.0277**
Anticonvulsants	16	7 (11)	6.42	6 (6)	0.511	0.4745
Transfusion	**15**	**4 (11.5)**	**3.25**	**2 (6)**	**10.98**	**0.0009**
Physiotherapy	14	9 (11)	5.94	5.5 (6)	0.025	0.8786
Extubation	12	9 (11)	5.015	9.5 (6)	0.604	0.437
A line	8	8.5 (11)	4.53	9 (6)	0.112	0.7378
CV line	7	8 (11)	7.05	8 (6)	0.210	0.6469
Intubation	7	6 (11)	6.87	1 (6)	2.071	0.1501
Muscle relaxants	7	8 (11)	5.15	8 (6)	0.008	0.9289
TPN	2	19 (11)	1.41	19 (6)	2.92	0.0873
LP	1	30 (11)	0.00	30 (6)	2.172	0.1405
CT Scan	1					

[a] Mean and median length of stay in brackets refer to patients *not* having the end intervention.

Table 25
Interventions in the Last 24 Hours of Life According to Severity of Disease

End Interventions N=165			Severity Category B[a] N=50		Category C N=114			
	N	%	N	%	N	%	χ2	P-value
IV fluids	133	81%	45	90%	88	77%	3.70	0.0545
IV antibiotics	**122**	**75%**	**44**	**88%**	**78**	**68%**	**6.95**	**0.0083**
N-G feeds	**99**	**60%**	**22**	**44%**	**77**	**67%**	**8.00**	**0.0045**
Nystatin	88	53%	24	48%	64	56%	0.92	0.3373
HBO_2	68	41%	23	46%	45	39%	0.61	0.4362
Morphine	**63**	**38%**	**11**	**22%**	**52**	**46%**	**8.14**	**0.0043**
Panado	51	31%	17	34%	34	30%	0.28	0.5959
Oral antibiotics	**44**	**27%**	**8**	**16%**	**35**	**31%**	**3.86**	**0.0494**
NPO_2	45	27%	13	26%	32	28%	0.07	0.7850
Venipuncture	**40**	**24%**	**23**	**46%**	**17**	**15%**	**18.10**	**0.0000**
Steroids	35	21%	11	22%	24	21%	0.02	0.8918
Nebulisation	31	19%	10	16%	21	18%	0.06	0.8126
Ventilation	29	18%	11	22%	18	16%	0.92	0.3386
Sedation	28	17%	8	16%	20	17%	0.06	0.8094
X-rays	**27**	**16%**	**17**	**34%**	**10**	**9%**	**15.99**	**0.0000**
CPR	24	15%	11	22%	13	11%	3.10	0.0780
Ringers lactate	**24**	**14%**	**16**	**32%**	**8**	**7%**	**17.26**	**0.0000**
Inotropes	**21**	**13%**	**14**	**28%**	**7**	**6%**	**14.78**	**0.0001**
Oral feeds	20	12%	6	12%	13	11%	0.01	0.9127
N-G tube	19	11%	9	18%	10	9%	2.87	0.0914
Anticonvulsants	16	10%	6	12%	10	9%	0.41	0.5225
Transfusion	**15**	**9%**	**12**	**24%**	**3**	**3%**	**18.98**	**0.0000**
Physiotherapy	14	8%	3	6%	11	10%	0.59	0.4413
Extubation	12	7%	2	4%	10	9%	1.16	0.3484
A line	8	5%	2	4%	6	5%	0.12	0.7303
CV line	8	5%	2	4%	6	5%	0.61	0.5383
Intubation	**7**	**4%**	**6**	**12%**	**1**	**1%**	**10.46**	**0.0034**
Muscle relaxants	7	4%	3	6%	4	3%	0.52	0.4688
TPN	2	1%	0	0%	2	2%		
Lumbar Puncture	1	1%	1	2%	0	0%		
CT Scan	1	1%	0	0%	1	1%		

[a]Category A (1 patient) is excluded from the Table.

24 hours (46% versus 22%; P=0.0043). Procedures such as venipunctures and X-rays were at least 3 times more likely among Category B than Category C patients (respectively 46% versus 15%; P=0.0000 and 34% versus 9%; P=0.0000). In similar vein, resuscitative and life-sustaining treatments such as Ringers lactate and inotropes in the last 24 hours were almost 5 times more common in Category B than Category C patients (respectively 32% versus 7%; P=0.0000 and 28% versus 6%; P=0.0001). In line with these findings there was a non-significant tendency for more patients in Category B than Category C to receive CPR (22% versus 11%; P=0.0780). By the same token a life saving intervention such as intubation in the final 24 hours was significantly more common in Category B than Category C patients (12% versus 1%; P=0.0034). Given that only 7 patients were intubated in their last 24 hours, this finding must be interpreted cautiously.

3.3.2 Interventions in the Last 24 Hours of Life and Location of Death

Significant associations between interventions in the last 24 hours of life and location of death are highlighted in Table 26. As anticipated, certain interventions occurred exclusively within the intensive care setting: ventilation, A lines, CV lines, extubation and use of muscle relaxants. Two patients were intubated in a general ward prior to being transferred to the PICU. However, other treatments were offered significantly more frequently in the PICU. These included morphine (68% versus 30%; p=0.0000), steroids (38% versus 7%; P=0.0065), sedation (53% versus 8%; P=0.0000), inotropes (41% versus 5%; P=0.0000), CPR (38% versus 8%; P=0.0000), blood transfusions (26% versus 4%; P=0.0000) and physiotherapy (32% versus 2%; P=0.0000). Procedures such as venipunctures and X-rays were also twice as likely to take place in the last 24 hours if patients died in the intensive care unit (respectively 41% versus 20%; P=0.0099 and 29% versus 13%; P=0.0213). In contrast, the use of Nystatin, HBO_2, and oral antibiotics as final interventions was significantly more common in the general wards (respectively 53% versus 32%; P=0.0060, 49% versus 12%; P= 0.0000, and 31% versus 9%; P=0.0084).

The 5 most common end interventions in the PICU included IV fluids (91%), IV antibiotics (88%), ventilation (85%), morphine (68%) and sedation (53%). In comparison, IV fluids (78%), IV antibiotics (70%), N-G feeds (62%), Nystatin (59%) and HBO_2 (49%) were the 5 main treatments offered to patients in the general wards. Morphine, administered to 30% of patients, ranked only eighth in the general wards.

3.3.3 Association between Interventions in the Last 24 Hours of Life and End of Life Decisions

Associations were examined between interventions in the last 24 hours and documentation of DNR orders, evidence of dying and comfort care plans. Additionally, associations were examined between interventions in the last 24 hours and documentation of several end of life decisions in the same patient, namely a DNR order plus evidence of dying plus a comfort care plan. Finally the effect of having *no* end of life decisions on end interventions was determined. Findings from these analyses are reported in Tables and Appendices. Significant and non-significant associations between end (i.e. in last 24 hours) interventions and presence of a DNR order, evidence of dying and a comfort care plan are detailed in Appendices 5 to 7.

Table 26
Interventions in the Last 24 Hours of Life According to Location of Death

	N=165		General Ward N=131			PICU N=34			
	N	%	N	%		N	%	$\chi 2$	P-value
IV fluids	133	81%	102	78%	31	91%	3.04		0.1320
IV antibiotics	122	75%	92	70%	30	88%	4.51		**0.0336**
N-G feeds	99	60%	82	62%	18	53%	0.98		0.4253
Nystatin	88	53%	77	59%	11	32%	7.53		**0.0060**
HBO_2	68	41%	64	49%	4	12%	15.23		**0.0000**
Morphine	63	38%	40	30%	23	68%	15.66		**0.0000**
Panado	51	31%	45	34%	6	18%	3.51		0.0611
Oral antibiotics	44	27%	41	31%	3	9%	6.97		**0.0084**
NPO_2	45	27%	39	30%	6	18%	1.99		0.1585
Venipuncture	40	24%	26	20%	14	41%	6.65		**0.0099**
Steroids	35	21%	22	17%	13	38%	7.38		**0.0065**
Nebulisation	31	19%	27	21%	4	12%	3.04		0.0811
Ventilation	29	18%	0	0%	29	85%	29.89		**0.0000**
Sedation	28	17%	10	8%	18	53%	39.09		**0.0000**
X-rays	27	16%	17	13%	10	29%	5.30		**0.0213**
CPR	24	14%	11	8%	13	38%	19.22		**0.0000**
Ringers lactate	24	14%	17	13%	7	20%	1.25		0.2634
Inotropes	21	13%	7	5%	14	41%	31.02		**0.0000**
Oral feeds	20	12%	19	14%	1	3%	3.37		0.0664
N-G tube	19	11%	15	11%	4	12%	0.00		0.9593
Anticonvulsants	16	10%	13	10%	3	9 %	0.04		0.8472
Transfusion	15	9%	6	4%	9	26%	15.56		**0.0000**
Physiotherapy	14	8%	3	2%	11	32%	31.23		**0.0000**
Extubation	12	7%	0	0%	12	35%	49.86		**0.0000**
A line	8	5%	0	0%	8	23%	18.83		**0.0000**
CV line	8	5%	0	0%	8	23%	18.83		**0.0000**
Intubation	7	4%	2	1%	5	15%	11.47		**0.0007**
Muscle relaxants	7	4%	0	0%	7	20%	18.83		**0.0000**
TPN	2	1%	0	0%	2	6%			
Lumbar puncture	1	1%	1	1%	0	0%			
CT Scan	1	1%	0	0%	1	3%			

Percentage distributions between end interventions and presence of a DNR order, evidence of dying and a comfort care plan are presented in Table 27.

Table 27
Percentage Distribution of Interventions in Last 24 Hours of Life According to Presence or Absence of a Do Not Resuscitate Order, Evidence of Dying and a Comfort Care Plan [a]

	Total Interventions	DNR		Evidence		Comfort Care Plan	
		Yes	No	Yes	No	Yes	No
	N	N	N	N	N	N	N
	165	138	27	83	82	73	92
IV fluids	81%	80%	81%	80%	82%	**73%**	**87%**
IV antibiotics	75%	75%	70%	70%	78%	**62%**	**84%**
N-G feeds	60%	**67%**	**26%**	61%	58%	66%	55%
Nystatin	53%	57%	37%	53%	54%	56%	51%
HBO_2	41%	**47%**	**18%**	41%	41%	38%	42%
Morphine	38%	40%	26%	**53%**	**23%**	**47%**	**31%**
Panado	31%	**34%**	**15%**	31%	41%	27%	34%
Oral antibiotics	27%	28%	22%	28%	23%	33%	22%
NPO_2	27%	28%	26%	29%	30%	26%	28%
Venipuncture	24%	22%	37%	19%	26%	**15%**	**31%**
Steroids	21%	21%	22%	25%	26%	**12%**	**28%**
Nebulisation	19%	20%	15%	27%	29%	19%	18%
Ventilation	18%	**13%**	**41%**	17%	17%	**9%**	**24%**
Sedation	17%	17%	18%	20%	13%	14%	19%
X-rays	16%	**13%**	**33%**	13%	19%	12%	19%
CPR	14%	**9%**	**44%**	**6%**	**23%**	**4%**	**23%**
Ringers lactate	14%	**12%**	**30%**	**8%**	**20%**	11%	17%
Inotropes	13%	**7%**	**41%**	**7%**	**18%**	**7%**	**17%**
Oral feeds	12%	13%	7%	16%	9%	16%	17%
N-G tube	11%	9%	22%	13%	10%	7%	15%
Anticonvulsants	10%	9%	11%	13%	6%	14%	6%
Transfusion	9%	7%	18%	5%	13%	**4%**	**13%**
Physiotherapy	8%	7%	15%	11%	6%	4%	10%
Extubation	7%	7%	11%	**12%**	**2%**	7%	8%
A line	5%	6%	0%	7%	2%	4%	5%
CV line	5%	4%	7%	7%	2%	4%	5%
Intubation	4%	**2%**	**15%**	1%	7%	3%	5%
Muscle relaxants	4%	4%	4%	5%	4%	1%	6%
TPN	1%	1%	0%	1%	1%	0%	1%
Lumbar Puncture	1%	1%	0%	1%	0%	0%	1%
CT Scan	1%	0%	0%	1%	0%	0%	1%

[a] Highlighted percentages indicate that there was a significant association between the end interventions and end of life decisions. Frequency distributions and significance levels of all associations are given in Appendices 5-7.

Patients with a DNR order were at least twice as likely compared to patients without an order to receive nasogastric feeds (67% versus 26%; P=0.0000), HBO_2 (47% versus 18%; P=0.0090) and Panado (34% versus 15%; P=0.0485). On the other hand, patients with a DNR order were significantly less likely to be resuscitated (9% versus 44%; P=0.0000), ventilated (13% versus 41%; P=0.0005), intubated (2% versus 15%; P=0.0029), given Ringers lactate (12% versus 30%; P=0.0153) or an X-ray (13% versus 33%; P=0.0093). (Table 27 and Appendix 5)

Likewise, patients with documented evidence of dying compared to those with no evidence were significantly less likely to receive CPR (6% versus 23%; P=0.0018), Ringers lactate (8% versus 20%; P=0.0255) and inotropes (7% versus 18%; P=0.0335). In turn, patients who were identified as dying were 5 times more likely to be extubated (12% versus 2%; P=0.0178) and twice as likely to receive morphine (53% versus 23%; P=0.0000). (Table 27 and Appendix 6).

With the exception of morphine, patients with a comfort care plan were significantly less likely to receive several interventions in the last 24 hours. These interventions included resuscitation (4% versus 23%; P=0.0007), ventilation (9% versus 24%; P=0.0166), a blood transfusion (4% versus 13%; P=0.0442) or a venipuncture (15% versus 31%; P=0.0146). Although the proportions of patients receiving the following interventions remained relatively high, significantly fewer patients with comfort care plans received IV fluids (73% versus 87%; P=0.0209), IV antibiotics (62% versus 84%; P=0.0013), steroids (12% versus 28%; P=0.0131) and inotropes (7% versus 17%; P=0.0442). In contrast, almost 50% of patients with a comfort care plan compared to 31% without a plan received morphine in the last 24 hours (P=0.0487). (Table 27 and Appendix 7). Even though patients with comfort care plans were *statistically* less likely to receive certain invasive treatments, from a *patient* perspective, 11 patients had blood drawn, 5 received inotropes, 3 were resuscitated and 3 underwent blood transfusions in their last 24 hours of life (despite having comfort care plans). Moreover, approximately three quarters and two thirds of these patients respectively received IV fluids and IV antibiotics. Almost twice as many patients received IV antibiotics rather than oral antibiotics in their last 24 hours, despite having comfort care plans (N=45, N=24 respectively).

The frequency of end interventions for patients with a comfort care plan in the longest length of stay quartile (≥16 days) is shown in Table 28. In descending order of frequency the most common end interventions received by at least 30% of these patients were N-G feeds (79%), IV fluids, morphine and oral antibiotics (58% respectively), Nystatin (50%), Panado (46%), HBO_2 (42%) and IV antibiotics (37%). Approximately 1 in 3 patients was nebulised in the last 24 hours. Of note, more patients received oral antibiotics than IV antibiotics (14 patients and 9 patients respectively), and HBO_2 was 3 times more common than NPO_2 (10 patients and 3 patients respectively). Moreover, only 1 instance of a venipuncture, X-ray and CPR are reported among these patients. However, only 4 patients were having oral feeds. No patient underwent a blood transfusion. Additional interventions in the last 24 hours included Betadine x3, garlic x3, Acyclovir x2, TB medicines x2, Dactarin gel x1, and Joules solution x1. The timing of morphine administration in these patients was instructive. On average, patients with lengths of stay ≥16 days waited 31 days before receiving their 1st dose of morphine, with a median waiting time of 28 days between admission and 1st dose of morphine. The mean and median length of time between the 1st dose of morphine and death was 2 days and 0 days respectively. One patient received morphine for 14 days, with the remaining 13 patients taking morphine for 3 or less days. Although cell numbers were small, it is noteworthy that there were no statistically significant differences between end interventions received by patients with a comfort care plan compared to patients without a comfort care plan in this length of stay category (≥16 days).

Table 28
Frequency of Interventions[a] in the Last 24 Hours of Life According to Presence of a Comfort Care Plan and Length of Stay ≥16 days (N=24)

End Interventions	No.
N-G feeds	19
IV fluids	14
Oral antibiotics	14
Morphine	14
Nystatin	12
Panado	11
HBO_2	10
IV antibiotics	9
Nebulisation	7
Oral feeds	4
Steroids	3
NPO_2	3
Sedation	2
Ringers lactate	2
Venipuncture	1
Ventilation	1
X-rays	1
CPR	1
Inotropes	1
N-G tube	1
Anticonvulsants	1
Physiotherapy	1
Extubation	1
CVP	1

Patients (N=20) with no documented end of life decision (i.e. no DNR, no evidence of dying and no comfort care plan) had a 5-fold greater chance of being resuscitated in their last 24 hours of life (50% versus 10%; P=0.0000). (Appendix 8) These patients were also significantly more likely to receive other life-sustaining interventions such as ventilation (40% versus 14%; P=0.0050), inotropes (45% versus 8%; P=0.0000), Ringers lactate (35% versus 12%; P=0.0057) and intubation (15% versus 3%; P=0.0111). Furthermore these patients were much more likely to have an N-G drainage tube (30% versus 9%; P=0.0058) and X-rays (35% versus 14%; P=0.0165). Finally this small sub-set of patients was significantly less likely to receive N-G feeds (20% versus 65%; P=0.0000) and morphine (15% versus 41%; P=0.0232) and HBO_2 (15% versus 45%; P=0.0113) in their final 24 hours.

Life-sustaining interventions, in particular, ventilation, inotropes, and CPR, and invasive procedures such as venipunctures, are among the top 5 interventions in the last 24 hours of life for patients without an end of life decision. (Table 29) At least 40% of patients undergo these interventions. Moreover, morphine ranks among the bottom 2 interventions. Similarly, morphine receives a relatively low ranking among patients with a DNR order only. In contrast, morphine ranks among the top 5 interventions among patients with a DNR order plus evidence of dying plus a comfort care plan. Indeed these patients had a 2-fold better chance of receiving morphine in their last 24 hours than patients with a DNR order only (53% versus 25%; $\chi 2$ = 7.06, P=0.0078). Although IV fluids were the top ranked intervention for both groups of patients, patients with a DNR order only were significantly more likely than patients with comprehensive orders to receive this form of treatment (93% vs 74%; $\chi 2$ = 4.87, P=0.0273).

Additionally, patients with a DNR order only are significantly more likely to receive IV antibiotics than patients with a DNR order plus other end of life decisions (90% versus 64%; $\chi 2$ = 7.99, P=0.0047). Nevertheless two thirds of patients with a DNR order, identified as dying and with comfort care plans, still received this intervention. Although less than 1 in 5 patients with a DNR order only received CPR in the last 24 hours, no patients with a DNR plus other decisions

were resuscitated (17% versus 0%; $\chi 2 = 6.74$, P=0.0031). Twelve patients with a DNR order only, compared to 1 patient with a DNR order and other end of life decisions, had blood drawn, and a further 7 patients with a DNR order only compared to 1 patient with comprehensive orders had a blood transfusion (respectively $\chi 2 = 6.57$, P=0.0103 and $\chi 2 = 4.41$, P=0.0163).

Table 29
Percentage Distribution and Rank Ordering of Interventions in the Last 24 Hours of Life According to Presence or Absence of End of Life Decisions

	All Interventions N = 165		No Decision N = 20		DNR only[a] N = 40		DNR + Evidence + CCP[b] N = 47	
	%	Rank	%	Rank	%	Rank	%	Rank
IV fluids[c]	**81%**	**1**	**85%**	**1**	**93%**	**1**	**74%**	**1**
IV antibiotics	**75%**	**2**	**80%**	**2**	**90%**	**2**	**64%**	**3**
N-G feeds	**60%**	**3**	20%	8	**73%**	**3**	**68%**	**2**
Nystatin	**53%**	**4**	**50%**	**3**	**50%**	**5**	**57%**	**4**
HBO_2	**41%**	**5**	15%	9	**57%**	**4**	40%	6
Morphine	38%	6	15%	9	25%	8	**53%**	**5**
Panado	31%	7	20%	8	37%	6	28%	8
Oral antibiotics	27%	8	20%	8	15%	12	28%	8
NPO_2	27%	8	35%	6	22%	9	30%	7
Venipuncture	24%	9	**40%**	**5**	30%	7	8%	9
Steroids	21%	10	15%	9	25%	8	15%	10
Nebulisation	19%	11	10%	9	20%	10	21%	9
Ventilation	18%	12	**40%**	**5**	17%	11	11%	11
Sedation	17%	13	15%	9	17%	11	15%	10
X-rays	16%	14	35%	6	12%	13	4%	12
CPR	14%	15	**50%**	**3**	17%	11	0%	0
Ringers lactate	14%	15	35%	6	15%	12	6%	13
Inotropes	13%	16	**45%**	**4**	10%	14	2%	16
Oral feeds	12%	17	5%	10	10%	14	23%	8
N-G tube	11%	18	30%	7	5%	15	11%	11
Anticonvulsants	10%	19	5%	10	0%	17	11%	11
Transfusion	9%	20	20%	8	17%	11	2%	15
Physiotherapy	8%	21	15%	9	5%	15	6%	13
Extubation	7%	22	5%	10	2%	16	8%	12
A line	5%	23	0%	0	5%	15	6%	13
CV line	5%	23	0%	0	5%	15	4%	14
Intubation	4%	24	15%	9	5%	15	0%	0
Muscle relaxants	4%	24	0%	0	2%	16	2%	15
TPN	1%	25	0%	0	2%	16	2%	15
Lumbar Puncture	1%	25	0%	0	2%	16	2%	15
CT Scan	1%	25	0%	0	2%	16	2%	15

[a] Includes patients with a DNR order only, with no documentation of evidence of dying or a CCP.
[b] Includes patients with documentation of a DNR *and* evidence of dying *and* a CCP.
[c] 5 top rank ordered interventions are highlighted in each column.

3.4 Pain and Distress in the Last 48 Hours of Life

Excluding patients (N=34) who died in the PICU, pain and distress were documented in medical and nursing entries of 72 (55%) patients of whom 38 (53%) had a documented comfort care plan. Documentation of pain and distress was more common in nursing than medical notes. Documentation occurred in both sets of entries in 29% (N=21) of folders, in 53% (N=38) of nursing notes only and in 18% (N=13) of medical notes only.

Respiratory distress was the most common source of distress among patients with and without a comfort care plan, occurring respectively in 39% and 59% of patients. (Table 30)

Table 30
Pain and Distress in the Last 48 Hours of Life (N=72) [a]

Symptomatology[b]	Comfort Care Plan N=38		No Comfort Care Plan N=34	
	N	%	N	%
Respiratory distress	15	39	20	59
Oral and oesophageal candidiasis	11	29	16	47
Perianal ulceration and dermatitis	11	29	2	6
Herpes, skin lesions and abscesses	9	24	1	3
Abdominal distension	2	5	9	26
Other[c]	4	10	3	9

[a] Excludes patients who died in the PICU.
[b] Multiple symptomatology in some patients.
[c] Includes, for example, otitis, anxiety, self-reported pain.

Phrases such as 'battling to breathe', 'laboured breathing', 'extremely exhausted', 'still visibly distressed' and 'working very hard' indicate that shortness of breath created considerable distress in the last 48 hours of life in over 1 in 4 children (35/131) who died in the general wards. Painful skin manifestations of HIV disease were a further source of discomfort in almost 2 in 5 patients. Vivid descriptions such as 'riddled with extensive candida', 'skin excoriated', 'still looks horrible', 'abscess and distinct lesions – painful to touch', 'weak cry though in great pain', 'mouth and buttocks very sore', and 'dry bloody crusts on both lips' confirm the extent of morbidity. Though less common, abdominal distension, for example 'distended abdomen+++ (NEC)', was another cause of discomfort for 8% of patients. Verbatim entries of pain and distress are fully reported for patients with and without comfort care plans in Appendices 9 and 10 respectively.

Demographic and clinical characteristics of these patients are detailed in Appendices 11 and 12. Differences in demographic and clinical characteristics were examined between patients suffering pain and distress according to the presence of a comfort care plan. The average and median age of patients with and without a comfort care plan (respectively 12 months and 6 months and 8 months and 4 months) was not significantly different ($\chi 2 = 2.285$, P=0.1306). In line with a previously reported strong association between length of stay and presence of a comfort care plan, patients with a comfort care plan in this sub-group had on average longer terminal hospitalisations than patients without a comfort care plan (17 days versus 10 days; $\chi 2$

= 5.255, P=0.0218). Moreover, the median length of stay for patients with a comfort care plan was almost double that of patients without a comfort care plan (9 days versus 5 days). Furthermore, almost 2 in 5 patients (N=15) with documented pain and distress, even with a comfort care plan, fell in the longest length of stay quartile (16+ days). Severity was not statistically associated with the presence or absence of a comfort care plan among patients reported to be in pain and distress in the last 48 hours of life. Patients without a comfort care plan were also significantly less likely to have a DNR order and evidence of dying (79% versus 100%; $\chi 2 = 8.55$, P=0.0034 and 32% versus 68%; $\chi 2 = 9.22$, P=0.0024).

Use of mild analgesia was similar for both groups although 2 patients with a comfort care plan received Dolorol forte as an adjunct to Panado. However, in keeping with an earlier finding, patients with a comfort care plan were more than twice as likely to receive morphine in the last 24 hours of life (52% versus 20%; $\chi 2 = 7.75$, P=0.0053). Nonetheless, approximately 2 in 5 (N=16) patients with a comfort care plan received no analgesia in the last 24 hours despite documented pain and distress. In comparison, almost 3 in 5 (N=20) patients without a comfort care plan received no analgesia in the face of pain and distress. It is noteworthy that with the exception of morphine, there were no statistically significant differences in the care given to patients with and without a comfort care plan in the last 24 hours.

The timing of morphine administration amongst this sub-set of patients is informative. (Table 31)

Table 31
Timing of Morphine Administration in Patients with Pain and Distress in the Last 48 Hours of Life[a]

Record[b]	Admission to morphine (d)	Morphine to death (d)
With a CCP (N=20)		
26	1	1
32	49	2
34	36	0[c]
39	28	2
41	23	2
44	8	0
48	5	2
50	2	3
54	1	2
58	33	2
69	28	0
76	42	2
89	26	0
116	2	0
121	12	4
141	39	0
147	3	0
148	4	1
158	7	2
161	6	0
Without a CCP (N=7)		
11	25	1
36	6	0
43	5	0
74	1	0
106	12	0
144	80	8
150	2	0

[a] Excludes patients who died in the PICU.
[b] See Appendices 9 and 10 respectively for detailed symptomatology.
[c] Patient received morphine intermittently in 1st week of admission for trauma from a non-accidental injury.

Two in 5 (8/20) patients with a comfort care plan and 5 out of 7 without a plan received their first dose of morphine within hours of death. Despite verbatim reports of pain and distress over 48 hours, only 3 patients received morphine for 3 days or more. Indeed, excluding 1 patient admitted to the PICU, 10 patients with lengths of stay $\geq$ 23 days waited on average 37 days for their first dose of morphine (this represents a total of 373 hospital days). These patients received morphine for 2 or less days.

Detailed summaries of patients with comfort care plans show that irrespective of instructions advocating 'TLC', 'Palliation' and 'Supportive Care', a sizeable proportion of patients was in pain and distress in their last 48 hours of life, caused largely by dyspnoea and oral, oesophageal and perianal pain (Appendix 9). What is more, in about 20% of patients, analgesia was recommended in the comfort care plan but these orders were never written in the medicine charts. Seven patients failed to receive morphine and 1 patient was never given Panado. Thus 1 in 5 patients with explicitly described pain and distress failed to receive analgesia recommended in their comfort care plans.

Chapter 4: Discussion

4.1 Introduction

South Africa is experiencing one of the fastest growing HIV/AIDS epidemics in the world. According to the most recent national seroprevalence survey in October 1999,[120] 22.4% of women attending antenatal clinics were infected with HIV, potentially translating into the birth of approximately 75 000 HIV-infected infants in 2000. Among children, gains in under 5 mortality rates are noticeably reversed and escalating hospital admission rates and death rates further signify the impact of the AIDS pandemic. Chris Hani Baragwanath Hospital in Gauteng has seen a 7-fold increase in hospital admissions for children with HIV/AIDS, from a relatively low 2.9% in 1992 to 20% in 1997.[121] In rural KwaZulu-Natal, about one quarter (26%) of admissions to the paediatric hospital wards of a district hospital were children with HIV/AIDS.[122] In the Western Cape Metropole, which includes hospitals in Cape Town, Paarl and Worcester, a bed use census in March 1999 revealed that children with HIV/AIDS occupied 12% of acute beds in the region.[123] In certain hospitals in the region, such as Stellenbosch and Victoria Hospitals, 1 in 5 paediatric admissions was HIV-related. A recent newspaper report found over half the paediatric admissions to Coronation Hospital in Gauteng were HIV-related.[124] A prospective, case-controlled study found 14.5% of admissions to a PICU in Durban were HIV positive or had AIDS.[125] Similarly, HIV/AIDS accounted for respectively over one half and one quarter of all ward deaths in Chris Hani Baragwanath[121] and Red Cross Children's Hospitals.[53] Despite growing numbers, many researchers believe these figures underestimate the prevalence of paediatric HIV/AIDS in acute care public hospitals, since screening for HIV infection is not routinely undertaken.

In developing countries disease progression in children with HIV/AIDS occurs early and rapidly. In a retrospective record review (1990-1995)[57] to determine survival patterns in HIV-infected children, 72% of deaths occurred in children less than 12 months, with a median time from diagnosis to death of only 3 months. In similar vein, in a prospective hospital-based cohort of HIV-infected children in Durban,[126] 88% of deaths occurred in children under 1 year of age. Overall, in Sub-Saharan Africa, the probability of death by 12 months ranges from 0.23 to 0.35,[127] and HIV-infected children can expect, on average, at least 2 hospital admissions during their short life span.[57, 121, 122, 123] Against a background of increasing hospital admissions and deaths due to HIV/AIDS, decreasing caregiver morale and a lack of data on end of life care among children dying of HIV/AIDS, the present study aimed to describe end of life decision making during the terminal hospitalisation of children with HIV-related deaths in one children's hospital and to identify opportunities for improving quality of terminal care. To this end, the medical records of 165 patients (99% coverage) who died of HIV-related causes between February 1998 and June 2000 in RXH were reviewed.

Consistent with previous findings[57, 126] most (80%) patients who died were less than 12 months of age, of whom two thirds were 6 months or less. Although only 1 in 10 patients was older than 2 years, the mean length of survival (51 months) of this minority of patients was at least 5 times greater than the overall sample average (10 months) and almost 3 times longer than patients aged between 1 and 2 years. Thus chances of longer survival seem to improve in patients who live beyond 2 years even though these patients fall in Category C.

Although only 1 in 3 patients fell in Category B, these patients were younger, with shorter lengths of stay than patients in Category C (mean ages of 4 months and 12.5 months respectively, P=0.0000; and mean lengths of stay of 6 days and 13 days respectively,

P=0.0000). Counterintuitively, this implies patients in the moderate disease Category B are sicker than patients in the severe Category C. There are 2 possible explanations. First is the presence of undiagnosed and untreated *pneumocystis carinii* (PCP) pneumonia. PCP pneumonia is the most common life-threatening opportunistic infection in children with HIV/AIDS. PCP pneumonia can manifest at any age but 50% of reported cases with HIV infection occur in children less than 6 months of age. PCP pneumonia may be the first presentation of HIV-related disease and the first episode may be rapidly progressive and fatal. Untreated PCP pneumonia is invariably fatal in immunosuppressed patients.[128] PCP is an AIDS-defining disease, which places a patient in Category C. If PCP pneumonia is not yet diagnosed patients may be classified as belonging to Category B. Second, is the poor predictive significance for Category B, which comprises indicator diseases with widely different prognostic importance.[129] Based on a prospective follow-up study of 366 HIV-infected children, Galli and co-researchers[129] recommend the inclusion of, among others, anaemia, candidiasis, diarrhoea and persistent fever, diseases with a proven shorter survival, in a high-risk sub-Category B. The authors believe this would improve the predictivity of the classification system and bring it closer in line with clinical reality. In sum, very sick patients in Category B may either have had undiagnosed PCP pneumonia or have been unreliably classified as falling in Category B.

Whilst the average length of terminal hospitalisation was 11 days, at least half the patients died within 1 week of admission and 1 in 4 patients died within 3 days of admission. These data imply doctors have to make crucial end of life decisions for patients who on average are under 1 year of age and who die within 1 and a half weeks of admission. Put differently, at least 50% of end of life decision making is among patients who are 4 or less months of age, within 6 or less days of admission. One notable exception was about one quarter of patients who on average remained in hospital for almost 1 month (range 16 days to 88 days). Most (87%) of these patients, with average and median ages of 12 months and 5 months respectively, fell in Category C.

The implications of complex decision making in the face of diagnostic and prognostic uncertainty are explored in following sections. The major end of life decisions are examined in terms of their positive and negative impact on the quality of terminal care received by hospitalised children who died of HIV/AIDS. Ethical implications of these decisions are also examined.

4.2 End of Life Decisions: Positive Findings

Improving end of life decision making depends in part on the ability of clinicians to recognise patients are dying, and their readiness to limit aggressive treatment and plan comprehensive palliative care. Where sick children are concerned this cannot be easy: most patients who died in this study were infants who had been in hospital for less than 2 weeks. In fact, over half the patients had been hospitalised for less than 1 week. Thus it is encouraging that more than 4 out of 5 patients had a DNR order, 1 in 2 patients was identified as dying, and rather less pleasingly, only 2 in 5 had a documented comfort care plan. Only 12% of patients died with no specified limits on treatment. In about one quarter of patients the DNR order was the only end of life decision. Most patients with evidence of dying or with a comfort care plan had a DNR order (93% and 94% respectively). Less than one third of patients had a DNR order, evidence of dying and a comfort care plan. Despite the absence of formal policies on DNR orders or palliative care at RXH, doctors made key end of life decisions that benefited patients.

4.2.1 Do Not Resuscitate Orders

DNR orders are directives in the medical and nursing record that preclude the use of resuscitative measures, including ventilation, in the event of cardiopulmonary arrest. An important goal of the DNR order is to ensure clinicians decide on the medical and ethical appropriateness of resuscitation attempts before they are needed on the assumption that a better decision will be made if it is made by the clinician most familiar with the patient, and if it is made without the stress induced by facing a sudden arrest.[130] In this light, the high rate of DNR orders recorded in this study is gratifying. Since only 16% of patients who died did not have a DNR order, it is possible doctors are learning to withhold CPR and ventilation, highly invasive interventions, when they are unlikely to benefit the patient, and merely prolong dying. Furthermore, the finding that 84% of deaths in this study were preceded by a DNR order compares favourably with reported rates of 100% and 66% respectively among children who died of cystic fibrosis[9] and cancer[8] and neurological diseases.[35] There are no comparable data for children who died of HIV/AIDS.

Patients' age and severity of disease were not significantly associated with having a DNR order. That children with DNR orders had longer lengths of stay (on average 5 days) than patients without DNR orders may be due to treatment regimens that require at least a week before patients show a reasonable clinical response to treatment. Furthermore, many children with HIV/AIDS manifest a slower response to antibiotic treatment and some require prolonged antibiotic treatment. Accordingly, clinicians may be reluctant to issue a DNR order until certain that children are not benefiting from treatment. In other words, as the patient's prognosis becomes clearer with time, DNR orders are written in advance of impending death.[139]

In this sense, a DNR order becomes a 'marker' of death.[139] Indeed, imminent death, progressive, severe and unresponsive disease and even the terminology of dying (for instance, end stage AIDS, terminal, poor prognosis) were the most common reasons for writing DNR orders in this study. Imminent death or the 'no chance' situation, as a basis for forgoing life-saving interventions is supported by the policies of official paediatric associations in the US[18], the UK[21] and Europe,[22] as well as empirical findings.[27, 30-35] Essentially imminent death implies a patient's condition is continuing to deteriorate despite aggressive intervention and the patient is likely to die in the near future, despite continued treatment. In the same vein, the 'no chance' situation refers to a patient with such severe disease that life-sustaining treatment merely delays death and may even increase suffering. Therefore in this situation life-prolonging medical treatment is considered inappropriate. Illustrative examples used in this study include the following verbatim rationales: 'Advanced AIDS. Septicaemia (staph) and progressive disease not responsive to treatment', 'Clinical AIDS. Poor response to treatment for pneumonia', 'Futile treatment not in the interests of the child. Not improving despite the best we can do'. Interestingly, futility, a controversial assessment, was only cited twice, both instances in the PICU, as a reason for not actively resuscitating patients who already on ventilatory support were showing no improvement. Arguably, in both these examples the use of futility accorded with guidelines provided by the Society for Critical Care Medicine.[60] They recommend using futility as a reason for restricting interventions only in situations where treatment offers no physiological benefit to the patient. This seems to have been the case in this study. According to the Consensus Statement of the Bioethics Centre at Groote Schuur Hospital,[62] if a life-sustaining intervention is highly unlikely to promote a patient's meaningful survival, it can be considered futile. At no stage were quality of life criteria or scarce resources invoked as reasons to withhold resuscitation or ventilation in this study. Quality of life assessments are controversial because they are inherently subjective. There is no objective

way to determine that death would be preferable to continued survival. This is even more problematic in children where professionals and parents, rather than patients, must decide what constitutes an unacceptably poor quality of life.

Whilst it may seem self-explanatory that DNR simply means do not resuscitate or ventilate in the event of full cardiopulmonary arrest, the possibility that doctors might interpret DNR as do not treat represents a constant moral concern.[131] Consistent with the purpose of a DNR order, patients with DNR orders were significantly less likely to be resuscitated (9% versus 44%, P=0.0000), ventilated (13% versus 41%, P=0.0005), intubated (2% versus 15%, P=0.0029) or to receive inotropes (7% versus 49%, P=0.0000) or Ringers lactate, a resuscitation fluid (12% versus 30%, P=0.0153). As importantly, DNR orders do not result in 'no treatment'. On the contrary, IV fluids and IV antibiotics were the top ranked interventions received respectively by 93% and 91% of patients with DNR orders only. What is more, patients with a DNR order as the only specified order were relatively more likely than patients identified as dying and with comfort care plans to receive IV fluids (90% versus 74%, P=0.0273) and IV antibiotics (90% versus 64%, P=0.0047).

Conversely, patients with no specified limits on therapy are expected to receive all medically indicated interventions, including CPR. Among the minority of patients with no DNR orders, life-saving interventions, in particular CPR, ventilation and inotropes as well as invasive procedures such as venipunctures, were among the top 5 ranked interventions received in the last 24 hours. In the absence of a DNR order there is a presumption that favours treatment and patients should receive all medically indicated treatment. All patients are assumed to fall in this category unless it is otherwise noted in patients' records. Findings among this sub-set of patients supported this presumption.

In short, decisions not to initiate life-saving resuscitation, including mechanical ventilation, were common. Importantly, DNR decisions successfully targeted specific interventions such as CPR and ventilation, which were withheld. In comparison, patients with no DNR orders received these highly invasive interventions. Patients with DNR orders continued to receive other life-sustaining interventions, short of resuscitation.

4.2.2 Evidence of Dying and Comfort Care Plans

Theoretically at least, patients who are labelled as imminently dying ought to receive only interventions appropriate for dying patients. One in 2 patients in this study was explicitly described as terminally ill (43%), as having a poor prognosis (35%), end stage (17%) or as deteriorating with no improvement (5%). The only comparable findings come from an adult study in which 72% of patients were classed as dying during their terminal hospitalisation.[54] Patients categorised as dying in the present study were almost twice as likely to fall in Category C (P=0.0049) and were hospitalised on average at least 4 days longer than patients with no documentation of dying (P=0.0250). It seems plausible that as hospitalisation proceeds, doctors are able to gather more information, which allows them to refine their prognoses about individual patients. For example, a confirmatory diagnosis of PCP pneumonia, which places a patient in Category C, as well as clinical evidence of failure to respond to different treatment regimens may take at least a fortnight. Without reliable evidence, which takes time to collect, a clinician may be reluctant to document patients as dying. Appropriately, patients classified as dying were less likely to receive life-prolonging interventions such as CPR (P=0.0018), inotropes (P=0.0335) or Ringers lactate (P=0.0255). Fittingly, these patients were more than twice as likely to receive morphine in the last 24 hours of life. Interestingly, equal proportions (17%) of patients, with and without evidence of dying, were ventilated in the last 24 hours of

life. Importantly, patients characterised as dying were significantly more likely to be extubated shortly before death (P=0.0178). Since extubated patients were removed from intrusive machinery shortly before dying, this was a positive effect of having been identified as dying in the PICU.

Examination of verbatim DNR orders and verbatim evidence of dying reveals some redundancy, for instance the shared use of descriptions such as terminal illness, poor prognosis and progressive deterioration. This is not surprising since imminent death was the most commonly cited rationale for issuing a DNR order.

If a terminally ill child's best interests are to be served the AAP[18] recommends an individualised plan of care that focuses on the child's need for comfort and symptom relief to ease the process of dying rather than provision of life saving medical therapy. Less than half the patients in this study had a comfort care plan. Notably this finding is almost identical to that reported by Fin and co-researchers[54] where only 46% of adult patients who died in an acute hospital had a comfort care plan. That patients with a comfort care plan were much older (on average 14 months versus 7 months, P=0.0052), more likely to fall in Category C (51% versus 30%, P=0.0135), with significantly longer hospitalisations (on average 2 weeks versus about 1 week, P=0.0006) confirms clinicians' need for certainty, which takes time, before recommending a change in focus from 'cure' to palliative care. Clinicians may first exhaust all curative options, aimed at treating reversible conditions, before they consider palliative care.

Tender loving care, keeping patients comfortable and providing supportive care were the most common injunctions to redirect treatment towards palliation. Palliation and analgesia were specifically ordered in only 1 in 10 patients and only 1 plan included a directive to change the goals of treatment. In view of the vagueness of these directives, it was helpful that two thirds of comfort care plans included specific instructions to withhold or withdraw particular interventions (investigations, blood products, and IV antibiotics for instance) or, as importantly, to add comfort measures such as morphine, HBO_2, and sedation to current treatment regimens.

In keeping with other end of life decisions, namely DNR orders and identification of patients as dying, patients with comfort care plans were less likely to receive aggressive life-saving interventions such as CPR (P=0.0001), ventilation (P=0.0166) and inotropes (P=0.0412). Further, comfort care plans appeared to moderate the use of invasive procedures such as venipunctures (P=0.0146), and transfusions (P=0.0480). Impressively, comfort care plans significantly reduced the proportion of patients receiving IV fluids and IV antibiotics by 14% (P=0.0209) and 22% (P=0.0013) respectively. Even though about three quarters and two thirds of patients continued to receive IV fluids and IV antibiotics, these findings nonetheless confirm the usefulness of comfort care plans in reducing the scale of aggressive life-saving and life-prolonging interventions in patients' last 24 hours of life. At the same time comfort care plans significantly stimulated use of analgesia: almost half the patients with comfort care plans received morphine in their final 24 hours (P=0.0487).

4.2.3 Paediatric Intensive Care

The potential for discrimination against children with HIV/AIDS is a moral concern. For example, Levin *et al*[37] provide compelling evidence of discriminatory attitudes favouring withholding of medically needed treatment, for non-HIV-related conditions, from infants infected with HIV. Responding to hypothetical scenarios, 98% of neonatologists recommended life-

saving cardiac surgery for a neonate with duodenal atresia with no risk of HIV, but only 50% recommended such surgery for newborns known to be HIV-infected. The corresponding figures for chronic renal dialysis and resuscitation following cardiac arrest were 91% and 26% and 85% and 22% respectively. In contrast, neonatologists recommended IV fluids for both sets of patients, 99% and 93% respectively. Most respondents cited diminished quality of life as their main reason for non-treatment of HIV-infected infants. The highest median expected quality of life for these infants was lower than that for a premature infant weighing 625 grams at birth. Additionally, the median highest expected quality of life for an infant born to an HIV positive mother was equivalent to that of an infant with Down syndrome, yet most infants born to HIV positive mothers will have no disease.

In general, social factors such as stigmatisation and extreme poverty make an HIV-infected infant's life particularly vulnerable to devaluation. In SA, if children are known to be HIV positive, they may be refused admission to some PICUs, for example Chris Hani Baragwanath Hospital.[121] It is therefore encouraging that almost 1 in 4 HIV-infected children with reversible illness in this study was admitted to the PICU during the course of their terminal hospitalisation. Moreover, the unstable physiological condition that prompted admission to the PICU resolved in a sizeable minority (16%) of children who were returned to general wards, although they died later in the hospitalisation. Twenty one percent of all deaths in this study occurred in the PICU. Comparable data of deaths in PICUs of children with other chronic diseases show considerable variation, for example 45% of cancer deaths[8] and 11% of CF deaths.[9] Importantly, these data reflect practices in well-resourced countries. Arguably in SA given scarce resources and a poor prognostic outcome, comfort care is more appropriate for critically ill HIV-infected infants.

Patients who died in the PICU in this study were on average 6 months younger than patients who died in the general wards (P=0.0003). Survival rates in a Cape Town-based sample[57] show that HIV-infected children diagnosed under 6 months of age have a significantly shorter median survival (10 months) compared with 36 months for children diagnosed at 7 to 12 months of age. Younger infants in this sample had over a 4-fold greater risk of death than older children. HIV-infected children less than 6 months of age in Category C generally died within 2 months of diagnosis. These findings led Hussey and co-researchers to recommend palliative care in a primary care setting for HIV-infected children less than 6 months old with severe disease. They specifically recommend these children not be subject to hospital admission, and particularly not intensive or high care interventions.

In turn, Klein and Zar[132] argue that current data from developing countries on the long-term outcomes in HIV-infected children who receive intensive care do not support the exclusion of these children from admission to intensive care units solely because they are HIV positive. They identify 2 categories of HIV-infected children who can potentially benefit from intensive care: children with life-threatening conditions not considered complications of HIV infection (for example, croup), and children with life-threatening pneumonia and no clinical stigmata of AIDS. However, in line with Hussey *et al*,[57] they do reject as futile (and cruel) admission of children with advanced AIDS who are failing to thrive and have potentially lethal conditions associated with terminal disease.

At the time of death, 56% of patients in the PICU were under 6 months of age and fell in disease Category C. The HIV status of one quarter of these children was known prior to admission to the PICU. With the benefit of hindsight, it is easy to argue these patients should not have been admitted to the PICU in the first place. Against this it can be said these were critically ill patients who presented as medical emergencies and whose AIDS-defining illnesses were only diagnosed post-admission as patients rapidly deteriorated or who failed to respond to

intensive treatment. Thus decisions to admit these children were based on incomplete information. Severe respiratory disease accounted for three quarters of admissions to the PICU. Steroids were administered significantly more often in the last 24 hours of life among patients who died in the PICU. This suggests PCP pneumonia, an AIDS-defining illness, was suspected or confirmed in at least some of these patients. In a context of uncertainty, doctors adopted an individualised prognostic decision making strategy.[13] Patients are admitted to the PICU and constantly re-evaluated, using information accumulated in the course of treatment, as to whether continuing treatment is likely to benefit the patients. Compared to the statistical prognostic strategy where decisions to treat are based on statistical prediction of a patient's likelihood of benefiting from treatment, the individualised strategy is morally preferable because it focuses on the situation of the particular patient whose life is at stake and thus comports with the ethical precept that treatment decisions should be based on an individualised assessment of the patient's best interests. Practically speaking this entails ongoing assessment of whether provision or withdrawal of treatment is in the patient's best interests. Importantly, the individualised approach focuses on particular patients, which entails agonising deliberations that are commensurate with the moral weight of the decisions involved.[13] Still, some may argue that in terms of time and energy allocated to decision making and the resources allocated to the resulting treatment, an individualised prognostic strategy, while ethically preferable is practically unfeasible.

Ultimately, the increasing burden of HIV on scarce hospital resources may compel the PICU at RXH to develop admission and discharge[59] criteria for HIV-infected children based on the best available evidence and following acceptable procedural guidelines. Arguably, in the interests of fairness, such criteria ought to be developed for all children admitted to PICUs because intensive care is a costly and scarce resource. However, decisions about which categories of patients should receive or be denied intensive care, based on considerations of resource use, are social policy deliberations and should only be made after considerable public discussion, not ad hoc at the bedside.[60] In SA, macro-level policies to limit children's access to expensive tertiary services must consider Constitutional guarantees of equal access to basic health care services which in the case of chronically ill children, may include services beyond the minimum requirements defined in a basic health care package.[133] Additionally, at the micro-level, a recent Constitutional Court judgement suggests administrative and distributive justice requires explicit justificatory criteria if access to limited resources is to be fair and transparent.[134]

As to be expected, once admitted to the PICU, these children received significantly more invasive interventions such as CPR, intubation, ventilation, A lines, CV lines and blood transfusions until the time of death (P=0.0000, P=0.0007, P=0.00000, P=0.0000, 0.0000). Similarly, patients in the PICU underwent more diagnostic procedures such as venipunctures and X-rays in the last 24 hours of life (P=0.0099 and P=0.0213). Physiotherapy is a routine intervention in the PICU and would explain the higher proportion of children receiving this treatment compared to children in general wards (P=0.0000). Likewise, as already noted, steroids are an essential adjuvant therapy if PCP pneumonia is suspected or diagnosed.

In comparison, the care of the child identified as dying in the PICU requires a dramatic shift from rescue mode to approaches that recognise death's inevitability and focus on patient and family comfort.[86] Some hospitals have palliative care units for patients whose life-sustaining treatment is withdrawn, for example, the Butterfly Room at the University of Texas Medical Branch at Galveston. Wall-papered with butterflies, this home-like suite is quite different from other hospital wards and can be used for PICU patients who are expected to die within minutes to days following extubation. Children transferred to the Butterfly Room undergo no laboratory or invasive investigations, routine monitoring is discontinued and they receive only medications

that contribute to their comfort. Young patients are extubated whilst sitting on their parents' laps.

One in 2 patients was identified as dying in the PICU and less than one third had a comfort care plan. Defining a comfort care plan in an intensive care setting is difficult. In this study a comfort care plan reflected a decision to extubate and focus on palliation: for example, comfort care plans stated 'Palliative care. Extubation. Morphine and midazolam to prevent agonal breathing', 'Supportive care. Change goals. Withdraw curative care. Morphine infusion', Keep comfortable with morphine and Valium. Withdraw curative treatment on grounds of futility'. One in 3 patients was extubated and removed from the ventilator prior to death. A decision to extubate was taken only after full discussion with a patient's parents. Extubation permitted the removal of unwanted machinery and parents were able to hold their child as he or she died. Prior to extubation, patients received a bolus infusion of morphine to reduce suffering and facilitate a peaceful death.

Finally, decisions to stop ventilation are morally justified on several grounds.[135] First, ventilation is generally meant as a temporary bridge until a patient recovers sufficiently to survive without ventilation. If a patient's condition deteriorates and it is apparent the patient will not be successfully weaned then continued ventilatory support becomes pointless. If ventilation serves only to prolong dying, it should be stopped. Second, continued ventilator support may be unduly burdensome if a patient is imminently dying. Measurement of pain and suffering in mechanically ventilated infants is not possible and the presence of ventilation equipment prevents cuddling and holding in the terminal stage of disease. Thus ventilation impairs communication. Third, the economic cost of mechanical ventilation, coupled with intensive care, may be questioned when patients are imminently dying.

In summary, well over 80% of patients had a DNR order, which prevented inappropriate resuscitation and ventilation. In turn, patients with no specified restriction on treatment received all medically indicated interventions, including CPR and ventilation. Fifty percent of patients were identified as dying and appropriately were less likely to receive life prolonging interventions such as CPR, whilst being more likely to receive morphine. Although only 2 in 5 patients had a comfort care plan, these orders prevented patients from receiving aggressive life-saving interventions, reduced the scale of patients receiving IV therapies and increased the likelihood of morphine use. Almost one quarter of patients with reversible illness were admitted to the PICU during their terminal hospitalisation, suggesting that intensive care was not withheld from patients if it were felt they would benefit from intensive care-based interventions. Still, despite these positive findings, there is considerable room for improvement in terminal care as indicated by data presented in the following section.

4.3 End of Life Decisions: Negative Findings

4.3.1 Do Not Resuscitate Orders

RXH does not have a formal DNR policy. Hence decisions not to resuscitate depend on the clinical judgement of those caring for the patient. If such discretion is to be justified, it must be against a background of acceptable moral principles and guidelines. To this end, general procedural requirements that should accompany these orders are provided by, among others, the AAP[18] and the RCPCH.[21] In South Africa the Consensus Statement by the Bioethics Centre at Groote Schuur Hospital[62] recommends all decisions to forgo life-sustaining treatment

be fully and clearly documented in the notes, together with the rationale for the decision, and procedures followed in reaching the decision. In addition, decision making at the end of life should result from joint consultation between health care professionals, patients and families who may hold a range of cultural and religious beliefs.

The RCPCH[21] advises that the consultant-in-charge and a senior colleague (a nurse or a social worker) discuss the decision with parents and the child (as far as he or she is able). Furthermore, if parents are to be fully involved they need adequate time and information to understand and assess the information and obtain alternative advice if they so choose. Whilst the final decision is made with parental consent, generally the clinical team takes main responsibility for the decision to alleviate any burden of guilt parents may feel. In the British context, Doyal and Wishler[65] argue that consent could probably be waived in situations where the probability of successful resuscitation approaches zero. In such situations CPR can rightly be considered futile, and it is not part of a doctor's duty to administer useless or harmful treatment.

Practically speaking, failure to document and communicate decisions adequately means decisions such as those not to resuscitate will be made by default and frequently by persons least familiar with the patient.[135] Responsibility for participation in resuscitation decisions may change daily in teaching hospitals and potential misunderstanding increases with numbers of doctors, nurses and other allied professionals responsible for patient care.[130, 135] For example, Uhlmann *et al*[135] compared the original treatment withholding intentions of physicians who wrote DNR orders with the subsequent interpretation of the orders by cross-covering physicians. The set of interventions to be withheld was unique in 91% of cases. Although CPR (100%), mechanical ventilation (93%), intensive care (86%) and inotropes (77%) were the most commonly intended interventions to be withheld, physicians also intended blood transfusions (45%), antibiotics (23%), oxygen (20%) and IV fluids (14%) to be withheld. Whereas concordance was generally good for CPR (93%), ventilation (98%), intensive care (82%) and inotropes (75%), cross-covering physicians were far less likely to withhold blood transfusions (20%), antibiotics and oxygen (2% respectively). Unsurprisingly, the authors concluded that specific interventions to be withheld be explicitly documented in a readily accessible format and location.

In short, legal and ethical guidelines[65] require that DNR orders be clear and explicit, that a basis for the decision be documented, that the DNR order not affect provision of other appropriate care and, in the case of children, the parents' consent is obtained. Findings in this study highlight serious shortcomings in the documentation of DNR orders, which therefore fail to meet the best practice standards.

Compared with equivalent medical records, in over half the nursing records there was no documentation that a particular patient was not for resuscitation, and where DNR orders did appear contemporaneously, terminology was inconsistent in 45% of cases. For example, 16% of patients with DNR orders were described as 'Not for IPPV' by the clinicians and 'Not for active resuscitation' by the nurses. It can only be speculated whether it was intended that ambubagging, ventilation, or both be withheld. Likewise, 'Not for CPR', 'Not for active resuscitation', 'Not for Red Box' and 'Not for ambubagging' were used interchangeably. If these terms are equivalent instructions and understood as such by all clinical team members, then DNR orders using these terms are indeed similar in intent if not language. Yet, Uhlmann *et al*[135] report disagreement between physicians over the meaning of CPR, let alone substituting other terms which might or might not have equivalent meanings. DNR orders

instructing 'No heroics', 'No active management' or 'No active treatment' were so broad as to render them meaningless. Fortunately they occurred in only 2% of cases.

That a DNR order appeared simultaneously in only 2 in 5 medical and nursing notes should not be surprising given an earlier finding that doctors at RXH sought nurses' opinions about resuscitation in only 39% of cases.[51] It seems reasonable to conclude that nothing has changed. Yet decisions on resuscitation should not be made unilaterally. Nurses, in daily contact with patients, are well placed to advise on a patient's medical condition. Moreover, in the absence of a written DNR order, not calling a "Red Box' could place a nurse in an indefensible medico-legal position. In addition to reducing communication errors, shared decision making is likely to lead to better end of life decision making generally. For example, the RCPCH[21] proposes that all team members have an opportunity to voice their opinions about patient care although the consultant-in-charge of the case bears the final responsibility for decision making. Wisely, the College recognises that such discussions provide a valuable learning experience as senior team members interpret information that is shared in light of their previous experience whilst openly evaluating any new interpretations that are offered.

Although over half the DNR orders appeared prominently in the front of the medical notes, in the remaining folders in the event of an arrest, a doctor, unfamiliar with a patient, who tries to establish the patient's resuscitation status would face a time-consuming search of a patient's entire medical record. Nor could the doctor confidently rely on a nurse's knowledge because in about 50% of cases they have no record at all. In 2 instances, doctors-in-training documented their plight trying to establish a patient's DNR status. Their concern is justified by the finding that 6% of patients identified as dying had no accompanying DNR order. Arguably in the absence of a specified order restricting treatment, these patients would have received full medical treatment despite their terminal status. Furthermore, patients' suitability for resuscitation should be reviewed on every consultant ward round taking account of the views of all staff caring for the patient. Yet, contrary to accepted practice, junior doctors relied on DNR orders from previous admissions in 6% of cases. Finally, decisions not to resuscitate require clinical and ethical justification, yet approximately 40% of DNR orders in this study had no documented rationale. This is contrary to best practice standards recommended by the AAP,[18] RCPCH[21] and the Consensus Statement of the Bioethics Centre at Groote Schuur Hospital.[62] These combined shortcomings may account for 7 (17%) resuscitation attempts despite standing DNR orders. Such communication errors needlessly submit terminally ill children to highly invasive and inappropriate interventions. To be sure, miscommunication in any other category of doctors' orders, such as drug prescriptions, would not as easily go unnoticed.

Published data for children who died in hospital show uniformly high rates (>90%-100%) of documented discussion between clinicians and parents of treatment limitations.[9, 27, 28, 33] In comparison, in this study, documentation of a discussion of a DNR order with parents or a guardian occurred in less than 40% of cases. There are several possible explanations for this finding. Doctors may indeed have discussed DNR decisions with parents and simply failed to record the fact. Parents, many of whom are poverty-stricken, may have visited infrequently and the decision not to resuscitate needed to be taken urgently. Language barriers may have impeded communication. No matter the probable reasons, decisions about children should be taken in consultation with parents with due regard for their values, beliefs and preferences. The presumption is that parents make end of life decisions according to the best interests of their child, and have crucial knowledge of non-medical factors affecting those interests.

If DNR orders mean no resuscitation or ventilation if a patient arrests, then clinicians should also consider and clearly document what is to be done regarding patients' other concurrent

medical needs.[67] Importantly, a DNR order can be compatible with either maximal therapy short of resuscitation if these measures benefit the patients, or alternatively a DNR order may imply a patient ought to be allowed to die peacefully without any further diagnostic tests or curative interventions. Writing a DNR order should prompt clinicians to rethink all the goals of therapy.[54] Frequently the limitation of many other therapeutic interventions is appropriate and may even be preferred by the family.[67] Other positive steps such as adjustment of analgesia may also be appropriate. Additionally, attention to other treatment issues at the time of writing a DNR order may allay parents' fears that a DNR order implies no care at all and that the child will not be abandoned.

To this end, several studies have confirmed the usefulness of structured and procedure-specific DNR orders to minimise problems of communication and misinterpretation,[68-72] and improve quality of end of life care.[67] Whilst there is only 1 anecdotal report[16] of a structured paediatric DNR order in use in the Children's Hospital in Boston, a specific treatment plan to accompany the DNR decision including interventions to be withheld, withdrawn or initiated constitutes sound clinical practice. Ideally the family and clinical team would mutually agree on this plan. In turn, the procedure-specific DNR form would promote accurate and consistent communication of these decisions once they have been made. To broaden the focus beyond the DNR order, Fins et al[54] developed a structured treatment plan or Goal Assessment Tool.

4.3.2 Evidence of Dying

Doctors' prognostication is central to end of life decision making. If doctors are to administer appropriate care to a terminally ill child, they must first identify the child as dying. For example, a clinician's prognostic assessment that a child is terminal is necessary when deciding to withhold or withdraw life-saving interventions. Yet of the 165 patients who died in this study only 50% had documented evidence of dying. This was far fewer than the number of DNR orders prior to death (84%). There are several possible reasons to account for this finding.

Self-evidently, not all patients who die are terminally ill. On admission some patients who later die may require management that differs from terminal care. As previously mentioned, in the face of uncertainty much aggressive care will appear to have been non-beneficial only after death, when the perspective is quite different. With this in mind it is to clinicians' credit that 2 in 5 patients who died within a mere 3 days of admission were identified as dying. Doctors took on average 8 days to identify as dying patients with lengths of stay between 1 and 2 weeks. Patients in the longest length of stay quartile (16+ days) were not labelled as terminal until well over 3 weeks post-admission. Thus at one end of the spectrum about 1 in 4 patients has a short period of rapid decline and dies within days of admission, at the other end long stay patients follow a slowly dwindling course to death. These different trajectories confirm the unpredictable course of HIV/AIDS and clinicians may find it difficult to know for certain if a patient has reached a terminal phase. Whether further aggressive therapy is warranted in a seriously ill patient is one of the most difficult decisions a clinician makes daily. Faced with clinical uncertainty, 91.7% of a randomly selected sample of internists in the US were reluctant to make predictions about a patient's illness.[136] Thus it is not surprising that patients identified as dying in this study were more likely to fall in Category C ($P=0.0049$) and to have on average 4 days longer in hospital than patients without evidence of dying ($P=0.0250$). These data suggest doctors wanted reassurance that patients had clinical AIDS. In turn, severity (i.e. Category C disease) was associated with longer hospital stays ($P=0.0056$) and ELISA positive

status at the time of admission (P=0.0005). Both these findings may have decreased prognostic uncertainty.

Alternatively, doctors may have considered DNR orders as proxy measures of death. Therefore, evidence of dying may have been implicit in many patients with DNR orders but no documented evidence of dying. After all, most rationales underpinning DNR orders were premised on imminent death, and for at least half the patients, evidence of dying was documented within 1 day of issuing a DNR order. Indeed, Faber-Langendoen[40] considers a DNR order a logical first step in the process of forgoing life-saving treatment: if a patient is recognised as dying despite full treatment of the underlying disease, the patient ought not to be rescued when death occurs. In short, doctors may have felt more psychologically comfortable issuing an abbreviated DNR order (for instance Not for IPPV) than explicitly labelling a child as terminally ill or dying. Clinicians may avoid applying an honest label to a situation if they think negative outcomes will result.[137] Only 1 in 10 patients in this study was referred to as 'dying' per se. Moreover, survey findings from the US show most (85.6%) physicians feel it is more helpful to have an 'upbeat attitude' in discussions with patients and families, and only 5% would reinforce families' pessimistic perceptions.[136] (p. 2391)

Writing about their experiences trying to recruit subjects for a research pilot study in palliative care, Davis and Steele[138] were struck by some clinicians' resistance to identifying children as terminal even though these children were receiving palliative care for advanced cancer. Clinicians' main concern was that mothers would lose hope if the possibility of the child's death were openly acknowledged. Clinicians feared involvement in research would focus parents' attention on the child's death to the detriment of the child's quality of life during the limited time remaining. However, these authors rejected the doctors' explanation on grounds that mothers were denied the opportunity to make their own choices, parents' ill-conceived notions of palliative care as 'hopeless' care would be reinforced, and open discussion of a sensitive topic such as dying would be inhibited.

On the contrary, families can still be hopeful if goals of care are reoriented from a focus on cure to a focus on short-term achievements or any experiences that give meaning to the dying process. Importantly, in a culturally diverse society, identifying a dying child as dying acknowledges the situation and allows time for culturally dependent family rituals.[139] In this study, knowledge that their child was dying may have ensured more parents were at the bedside at the time of death. Forty five percent of children died with no family present. Research shows parents may deeply regret not being present when their child dies and those who are present benefit from the experience.[84]

Whilst it is commonly believed physicians know, or at least have the potential to know their patients are dying, evidence suggests doctors' prognostic assessments are often wrong and systematically overoptimistic. Indeed, Christakis and Lamont[140] found doctors overestimated survival by a factor of 5.3. In other words, if all the predictions had been divided by 2 they would have been marginally more accurate. Moreover, only 1 in 5 predictions was accurate. Adult AIDS patients were the least likely to have correct predictions. In keeping with these findings, some doctors in the present study may have overoptimistically assessed patients' chances of survival and therefore not identified them as dying. Worryingly, excessive optimism may cause doctors to delay use of palliative care and analgesia, and to persist in aggressive and pointless interventions aimed prolonging life.

Finally, data on doctors' self-reported attitudes show they dislike prognostication.[136] It is stressful, difficult and some feel ill equipped. For instance, over 90% of internists found it far

harder to make an accurate prognosis of the course of a patient's disease than to make an accurate diagnosis. Whereas only a minority (7%) felt inadequately trained in diagnosis, over half (56.8%) felt inadequately trained in prognosis. To be expected, physicians respond by avoiding prognostication in the first place. Analogously, if prognostication is difficult and stressful for internists, it is surely as difficult and stressful, if not more so, for doctors caring for children. Over two thirds of paediatric oncologists reported anxiety at having to tell parents their child was likely to die soon.[85] Feelings of anxiety were described as 'very strong' in one third of these respondents. Furthermore, one quarter of paediatric oncologists rated dealing with dying children as the worst part of their job. Most patients in the present study were under 12 months of age, so doctors may have been even more reluctant to 'give up', a reluctance fuelled by prognostic and in some cases diagnostic uncertainty.

Although most research implies doctors are responsible for faulty and inaccurate communication at the end of life, recent data indicate doctors are only partially responsible. Wolfe and her team[113] show parents reached an understanding that their child was dying and had no realistic chance of cure from cancer 3 months after explicit documentation of the fact by the primary oncologists. However, when both clinicians and parents recognised early on that a child had no hope of recovery, elements of palliative care were more likely to be integrated into the treatment plan. Paediatric oncologists also confirm families' unrealistic expectations and denial as causing the most difficulty in delivering appropriate end of life care.[85] Efforts to improve the quality of care at the end of life ought therefore to focus on facilitating earlier recognition and acknowledgement by both clinicians and parents that an illness is fatal and the prognosis uniformly poor. To this end, Wolfe and colleagues[113] were cautiously optimistic to find that the presence of a social worker or psychologist was linked to greater concordance in the timing of clinicians' and parents' understanding that a child had no realistic chance of cure. They tentatively speculate that an interdisciplinary approach enhances communication of lethal outcomes and palliative options. Although still preliminary, this finding nonetheless suggests social workers may play a valuable mediating role in communicating painful prognostic information. Since most (95%) patients in the present study were Black, language may have constituted a formidable barrier to dialogue. Social workers, through interpreters if necessary, can assist doctors in delivering sensitive information. Yet there was documented social work involvement in less than 40% of records. That only one third of contacts focussed on supportive counselling, which presumably included discussion of prognosis, is of equal concern.

In short, clinicians and parents need to acknowledge a child is dying, the sooner the better. Although some error in prognostication is unavoidable, excessive optimism may adversely affect patient care and may lead to inappropriate interventions to preserve a child's life even when the child is dying. For example, patients not identified as dying in this study were significantly more likely to be resuscitated (P=0.0018), to receive life-prolonging therapies such as Ringers lactate (P=0.0255) and inotropes (P=0.0335) and were significantly less likely to receive morphine (P=0.0000) in their last 24 hours of life. Transition to palliative care requires, among others, that clinicians confront the prognosis and their uncertainties about it, contend with possible parental denial or unrealistic expectations for cure (because aggressive treatment may have worked in the past), and weigh parents' distress at having their child labelled as dying.

4.3.3 Comfort Care Plans and Interventions in the Last 24 Hours of Life

Whilst it mirrors current practice in many acute care hospitals, it is unfortunate the medical model and the palliative model are portrayed as polar opposites. The medical model concentrates solely on the goal of cure and in the process neglects medicine's other goals such

as relief of suffering.[141] Additionally, the curative model is characterised by a distinctly analytical and rationalistic set of assumptions. For instance, clinical concerns are approached as puzzles to be solved and clinical encounters are opportunities for scientific inquiry. According to this view, cure is conditional on accurate diagnosis and treatment, which in turn is directed more towards the underlying causes of illness than outward manifestations such as symptoms. Likewise, treatments considered successful improve objective disease-related outcomes such as infection-free survival, whereas treatments that improve subjective and non-specific outcomes such as quality of life are deemed less important. If cure is the overriding goal of medical care, clinical investigation is seldom complete until the underlying pathophysiology is understood. According to the medical model, diagnosis and treatment are necessary and desired. Logically it follows that if a disease cannot be stopped or slowed down, a patient may be seen as 'untreatable' or 'beyond help'. As one comfort plan in this study disconsolately declared, 'TLC. Nothing more can be done for this baby'. Where cure is the overarching goal, death is the ultimate failure. Fifty percent of paediatric oncologists reported feelings of failure at the prospect of a patient dying within 6 months.

In contrast, the palliative model is concerned with the total care of patients whose diseases cannot be cured. Among its primary goals are relief of suffering and symptom control. It is zealously concerned with pain management even though pain may not be definitively verified or explained. In comparison, in the medical model, the uncertainty and subjectivity of an infant's pain and suffering pose a substantial barrier to accessing analgesia. According to the palliative model, a specific treatment is appropriate only if it is worthwhile from the patient's perspective, in other words it must be in the patient's best interests. As death approaches, the focus of palliative care includes the physical, social, psychological and spiritual needs of patients and their families. Thus on the face of it the curative and the palliative model seem unconnected.[141]

Eighty four percent of patients had a DNR order justified on grounds of imminent death. Purists in the palliative tradition might reasonably argue that if children were dying, which about half did within 2 days of issuing the DNR order, they should have received only palliative care. Yet examination of interventions in the last 24 hours of life shows impressive numbers of children continued to receive invasive diagnostic and therapeutic interventions even though they were imminently dying. Overall, for example, at least three quarters of patients received IV therapies, one quarter had blood drawn for diagnostic purposes and about one fifth received ventilatory support in their last 24 hours. Almost certainly this was harmful and contrary to these patients' best interests.

Fox convincingly proposes that no one model is ideal for all patients in all clinical circumstances. Rather the most suitable model reflects individual patients' needs and goals. For most patients, neither a purely curative nor a purely palliative model is altogether suitable. Writes Fox, 'Between the curative model and the palliative model lies an unnamed approach that supports all legitimate goals of medicine...and is willing to combine them in whatever manner best reflects the values of the individual patient'. (p. 763)

For argument's sake, a mainly curative approach is properly applied to very sick patients with or without a confirmed diagnosis, who present with reversible components of disease. Patients in this study most likely to receive invasive diagnostic therapeutic and PICU-based interventions in their final 24 hours were significantly younger (IV fluids, P=0.0389; IV antibiotics, P=0.0024; ventilation, P=0.0014; intubation, P=0.0058 and steroids, P=0.0034), with shorter lengths of stay (IV fluids, P=0.0023; IV antibiotics, P=0.0009, Ringers lactate, P=0.0018, inotropes, P=0.0006; N-G tubes, P=0.0277; transfusions, P=0.0009, venipunctures,

P=0.0004 and X-rays, P=0.0168) and classified in disease Category B (IV antibiotics, P=0.0068; Ringers lactate, P=0.0000; inotropes, P=0.0001; intubation, P=0.0034; venipunctures, P=0.0000 and X-rays, P=0.0000). In general, median ages of patients who received these interventions were low (between 3 and 4 months) and median lengths of stay were short (2 to 6 days). On admission, HIV positivity of Category B patients was unlikely to be proven. Further, the terminal hospitalisation may have been the first hospital admission in many Category B patients. In sum, clinicians had to make crucial medical decisions about gravely ill infants in the presence of immense clinical uncertainty.

Several clinical manifestations of HIV disease are associated with early age and determine the intensity of treatment regimens. PCP pneumonia, a common initial presentation of HIV/AIDS, peaks in incidence between 4 and 6 months. The first episode of PCP pneumonia may be fatal. Early diagnosis of PCP pneumonia can be difficult and often relies on empirical trials of therapy. If suspected, then IV antibiotics must be instituted immediately. Indeed, IV antibiotic therapy should be started as soon as a diagnosis of PCP pneumonia is considered and should not wait until a definitive diagnosis is made. In patients with PCP pneumonia and acute respiratory failure, there is a markedly improved survival rate associated with adjuvant corticosteroid therapy.[132] Emergency evaluation of respiratory failure requires, among others, a complete blood count and differential, induced sputum for bacterial culture and a chest X-ray. Patients with suspected PCP pneumonia must be monitored closely. Deterioration in clinical status or a failure to improve within 24 to 72 hours should prompt reconsideration of the underlying diagnosis. Diarrhoea, acute or chronic, is another common problem in HIV-infected children. Acute diarrhoea can cause dehydration, especially if accompanied by vomiting and fever. Chronic diarrhoea and wasting may make an HIV-infected child more prone to dehydration from an intercurrent infection. Dehydration requires aggressive treatment with IV fluids, including bolus doses of resuscitation fluid such as Ringers lactate, and vasopressor support if necessary. An N-G tube may be needed to relieve abdominal distension. After fluid resuscitation, fluid and electrolyte deficits should be replaced intravenously over a period of 24 to 48 hours, and over 48 to 72 hours if patients were hypernatremic.

In short, the intensity of diagnostic and therapeutic interventions received by many infants in disease Category B within 1 week of admission is dictated and justified on grounds of clinical uncertainty, a high likelihood of PCP pneumonia and treatment regimens whose efficacy requires prompt intravenous administration of medications over a minimum of several days. The rapidity of deterioration, coupled with uncertainty, likely made a decision to stop curative care in favour of palliative care difficult despite the fact these children later died.

That said, of patients who suffered pain and distress in their final 48 hours, 57% (N=41) were aged 5 or less months, 47% (N=34) had lengths of stay less than 1 week, and 36% (N=25) fell in disease Category B. (Appendices 11 and 12) If infants show severe symptoms of distress such as shortness of breath or oral or abdominal pain, analgesia ought to be added to their treatment regimen even though the primary goals of intervention at this early stage are aimed at reaching a diagnosis and management of intercurrent illness. Yet, findings show patients most likely to receive morphine and Panado had significantly longer lengths of stay (median >1 week, P=0.0455) and fell in disease Category C (46% versus 22%, P=0.0052). Conversely, patients who died without a comfort care plan were significantly younger (median ages of 4 months versus 6 months, P=0.0052) and had far shorter terminal hospitalisations (5 days versus 9 days, P= 0.0006).

Because it is not possible consistently and accurately to predict the timing of death, it may be necessary to integrate palliative care early in a patient's course of illness, often in the face of

substantial clinical uncertainty. Importantly, parents may not have to fully acknowledge their child's poor prognosis to be willing to accept palliative treatments that lessen suffering. Wolfe *et al*[113] show that parents of children with advanced cancer concurrently accepted dual goals of cure and symptom relief to reduce suffering, and curative therapy to extend life. In similar vein, Robinson and colleagues[9] offer a 'mixture' of preventive, therapeutic and palliative care to their dying CF patients, 86%, 75% and 72% of whom respectively received opiates, IV antibiotics and vitamin preparations in the last 12 hours of life. They viewed this multifaceted approach as 'a viable alternative to the comfort care paradigm'. (p. 208) Likewise, Oleske and Czarniecki[89] advocate the early introduction of palliative care in tandem with antiretroviral therapies and treatment of opportunistic infections for HIV-infected children. They reject the view that palliative care should be reserved for end of life care when curative treatment is no longer possible.

Whilst these views appear incompatible with the traditional model of palliative care that involves a definitive transition from curative to supportive care, there is a growing consensus[87, 89] that among patients with life-threatening illness, accompanied by prognostic uncertainty, palliative care should be integrated early and concomitantly with treatment of underlying disease. Theoretically there may be nothing wrong with focusing narrowly on a single goal of medicine, be it cure or palliation. In practice, as data from this study show, overreliance on a single, especially curative approach, can have unanticipated consequences such as unrelieved pain and distress at the time of death.

However, the conclusion that some patients warranted a mixed management approach is a limited one. Many other patients, at least 44% according to instructions in doctors' notes, required comfort measures only. Doctors ordered these patients receive TLC, supportive care, conservative management and the like. If documentation of a comfort care plan signals a major shift in management goals from prolonging life to a primary concern for comfort, a complete reassessment of patients' care should follow: from diagnostic investigations, to medications, to discontinuing therapies that do not contribute to the goals of palliation. Yet of patients with comfort care plans, 73% continued to receive IV fluids, 15% and 13% respectively underwent venipunctures and X-rays for diagnostic purposes, and almost twice as many patients received IV rather than oral antibiotics in their final 24 hours of life (62% versus 33%). Patients with a comfort plan were as likely as those without to receive oral feeds only slightly more likely to receive morphine close to death.

Although not examined in relation to presence of a comfort care plan, only 22% and 2% respectively of parents received bereavement counselling from social workers or spiritual intervention during their terminal hospitalisation. Arguably, the need for spiritual and bereavement support is an individual matter best decided by parents themselves. Meert *et al*[84] found a minority of parents participated in a Bereavement Support Group held at the hospital where their child died. Reasons given for not attending included lack of transport, not wanting to return to the place where their child died, and no need to attend. Still, these services should be offered to parents who feel they can benefit from them.

Overall, designating patients to receive comfort care did not always correspond well with the care subsequently given, indicating that this decision alone does not translate into a consistently palliative care plan.

Of great concern, was the finding that the presence of a comfort care plan made no difference whatsoever to the end of life care received by patients in the longest length of stay quartile (16+ days). That said, decisions to withhold medical treatments such as IV antibiotics and IV

fluids, though taken infrequently, were most likely to occur in this category of patients. Still, these patients had to wait over 3 weeks on average before a decision to withhold a medical intervention was made. By the same token, doctors took over 3 weeks to identify these patients as dying and to issue comfort care plans. It can only be speculated why decision making was delayed in these patients, 87% of whom had clinical AIDS. The advanced stage of HIV disease in children is characterised by multiple complications from opportunistic infections and resistant organisms requiring aggressive treatment regimens with IV medications spanning weeks.[142] Several organ systems may be affected producing many symptoms. Children who appear terminal can rally and live for months, whereas others die suddenly and unexpectedly. Moreover, experience with HIV disease is relatively limited and clinicians may be more willing to accept a greater burden of treatment to provide patients an opportunity for a longer life, and the possibility of future beneficial treatments. Thus quality of life issues may conflict with treatment decisions as clinicians trouble over whether treating a current complication will extend life or merely prolong dying. Plus, after long hospitalisations, doctors may be even more reluctant to acknowledge that patients, they have come to know well, are close to death. However, as the burdens of treatment escalate, other important moral considerations must be brought to bear on decision making. Prolonging life cannot be the only goal. Comfort too must receive priority.

Continued aggressive care and inadequate symptom control, particularly in long stay patients, where diagnostic and prognostic uncertainty is less problematic, raise several ethical dilemmas relating to restriction of life-sustaining treatment. As a rule, the best interest standard determines medical decision making for children. This entails providing treatment that preserves life and confers net benefit over harm.[24] Because treatment choices must be considered in relation to patients' overall condition, even though some treatments offer a reasonable expectation of physiological benefit, they may be withheld or withdrawn from patients who are dying. It follows that in certain clinical circumstances, a child with multiple organ failure for example, many treatments may be more burdensome than beneficial, thus futile. Still, even if clinical conditions for non-treatment in paediatric HIV/AIDS were carefully defined, decisions about what constitute best interests, and benefits and burdens, involve normative judgements as well as scientific fact and may be controversial. A gravely ill child may be on several types of life-sustaining interventions, any of which might be withdrawn. Clinicians planning to withdraw support must therefore make choices and their decisions may influence the rapidity, painlessness and dignity of patients' deaths.[40-44] Nor should parental costs of false hope, delayed anticipatory grieving and visual memories of their child invaded by technology be discounted.

The use of antibiotics in the last few days or weeks of life is particularly complex. Approximately two thirds and one third of patients with a comfort care plan respectively received IV or oral antibiotics in their last 24 hours of life. Decisions are difficult because it is not possible to definitively predict whether antibiotics will cure an opportunistic infection or, conversely, whether withholding them will result in earlier death. Antibiotics do not fall neatly into the category of life-sustaining treatments such as mechanical ventilation or enteral feeding. Sometimes it is hard to draw the line between what is life prolonging and what is symptom management. For instance, antibiotics may be considered part of palliation if life-threatening infections produce uncomfortable symptoms such as dyspnoea and cough in respiratory disease.[143] However, the rational use of antibiotics may lead to added burdens in the form of diagnostic tests and IV lines. Those (more often bioethicists than clinicians[78]) who feel there is no moral distinction between withholding and withdrawing treatment would likely recommend starting antibiotic therapy. If after several days treatment proves ineffective, it becomes

pointless to continue and may be withdrawn. Still, clinicians with a bias to treat may persevere since failure to treat, or a decision to stop treatment, is seen as abandonment. The distinction between not starting and stopping treatment is difficult to defend and may even be harmful if it leads to decisions not to begin treatments that may be useful, in order to reduce the risk of being locked into a treatment that cannot be terminated. Twenty-three out of 24 patients in the long stay quartile received IV or oral antibiotics, confirming the psychological and symbolic, if not philosophical, significance of this distinction.

The findings that almost 80% and 66% of patients with comfort care plans received IV fluids and N-G feeding, compared to 16% who received oral feeds, suggests decisions regarding artificial nutrition and hydration may be even more controversial, given the strong emotional and cultural associations that attach to food and liquid. Although it is argued that artificial nutrition and hydration must be given because they represent humane care, this is not an accurate analogy. Unlike eating and drinking, medically provided nutrition and hydration lack the pleasurable oral sensations and interpersonal contact associated with food and fluid intake, especially in infants and young children.[144] In addition, they are medical interventions that carry complications such as oedema, erosion of mucosa, increased respiratory secretions, and discomfort and risk of infection from IV lines. Indeed, the presence of an N-G feeding tube or passing a new tube would likely increase the burden of suffering among the almost 40% of children with painful oral and oesophageal candidiasis. The burden of technology was illustrated by an entry in the nurses' notes which indicated a 27th month old child had to be '...restrained because she is pulling oxygen tube out of her nose' (Record 48).

Artificial nutrition and hydration requires skilled nursing. Paradoxically, availability of skilled nursing and time pressures in acute hospitals may lead to overuse of artificial nutrition and hydration.[144] If replacing an empty drip is less time consuming than hand feeding an irritable infant, then artificial feeding may do more to lessen the load of nursing staff than to provide humane care to dying children. According to nursing records, mothers were present during the greater part of terminal hospitalisations and would surely have benefited from the opportunity to hand feed their dying children. Feeding by hand is an act of nurturing. Likewise, during hand feeding the caregiver may be more attentive and affectionate, talking to and playing with the child. The psychological effects of feeding techniques are especially important when the goal of care is palliation.[144] Similarly, mothers were well placed to manage adverse symptoms such as thirst and dry mouth through provision of sips of liquid and good mouth care.

If artificial nutrition and hydration only prolong the dying process in an imminently dying child, which in turn prolongs any suffering to the patient, then treatment produces more harm than good. In such circumstances limiting artificial nutrition and hydration can be justified on grounds of beneficence. However, this is a qualified conclusion that must take account of consent.[145] If parents are able to contribute to decision making, then the decision to withdraw treatment, in particular artificial nutrition and hydration, should be discussed with them. Such a decision should not ordinarily be implemented if there are strong parental objections. Because decisions to limit life-sustaining interventions are difficult, doctors should consider clinical review by an impartial senior clinician who is not part of the treatment team.

4.3.4 Presence of Pain and Distress in Last 48 Hours of Life

Consistent with previous reports of pain in children with HIV/AIDS,[39] pain and distress in the last 48 hours of life, documented mainly in the nursing notes (53%), occurred in over half (72/131) the patients who died in the general wards. Respiratory symptomatology and oral and oesophageal candidiasis were the most common sources of suffering occurring in

approximately one half and two fifths of patients with documented pain and distress. Despite documentation of pain and suffering, 28% of long stay patients waited on average 31 days before receiving their 1st dose of morphine. Once again, of the 20 patients in this quartile with evidence of pain and distress in their last 48 hours, documentation of suffering mostly appeared in nurses' notes only (70% of cases) (Appendices 11 and 12). If procedural pain associated with venipunctures and insertion of IV lines had been measured, the prevalence of pain in patients in their last 48 hours of life would likely have been much higher. According to 1 nursing entry, 12 hours before the patient died, 'Registrar and consultant tried all afternoon to resite the drip'. It also worth noting that in tertiary hospitals often the least experienced person has to perform diagnostic procedures such as drawing blood.

About one half (38/72) of patients with pain and distress had a documented comfort care plan. Despite evidence of pain and distress, only 1 in 5 patients without a comfort care plan received morphine in the last 24 hours of life (Appendix 10). International guidelines on palliative care specifically reject rigid distinctions between curative, life-prolonging care and palliative care precisely because they hinder timely and appropriate provision of palliation to dying children. In the face of clinical uncertainty, a mixed management approach, which combines the goals of cure and palliation, was clinically and morally indicated in these patients with no comfort care plans. For example, in addition to prescribing Nystatin for candidiasis, and antibiotics, oxygen therapy and nebulisation for respiratory distress, administration of morphine may have reduced some of the suffering experienced by these patients, as well as the anguish of parents who accompanied them through the dying process.

If achievement of the best quality of life and relief of pain and other symptoms are fundamental goals of palliative care, palliation failed in at least 2 in 5 patients with comfort care plans. Despite documented pain and distress, these patients received no analgesia whatsoever in their last 48 hours of life. Ironically, 1 comfort care plan instructed the clinical team '...to do nothing that will cause discomfort'. Staff did do nothing: morphine recommended in the comfort care plan was never administered to a 4-month old infant repeatedly noted by nursing staff to be 'recessing+++ (Record 22). Even when explicitly prescribed, instructions were ignored, and 1 in 5 patients failed to receive morphine. Furthermore, 2 in 5 patients (8/20) with a comfort care plan received their 1st dose of morphine within hours of dying, yet pain and distress had been documented for at least 2 days. Even if it were argued that orders such as TLC, Keep Comfortable or Supportive Care are too vague to ensure specific palliative interventions, this cannot justify the extent of no treatment, undertreatment and late treatment of explicitly described suffering.

Overall, 41% of patients received morphine during their terminal hospitalisation. Not surprisingly, given the nature of interventions patients who died in the PICU were not only more likely to receive morphine (P=0.0000), but it was administered sooner (median of 0 days from admission to 1st dose, P=0.0004) and for a longer period from the 1st dose until death (median 4 days, P=0.0000). In comparison, patients in general wards were hospitalised for a median of 6 days before the 1st administration of morphine was given for an average of 2 days (median <1 day) before death.

Available literature recommends that pain management in children with HIV/AIDS follow the WHO guidelines for pain management in children with cancer.[39] This includes around-the-clock rather than 'as needed' regimens and the use of potent analgesia according to the WHO analgesic pain ladder. In line with these guidelines, morphine was prescribed around the clock at 4 hourly, 6 hourly and 12 hourly intervals. That said, of patients for whom oral morphine was prescribed, almost one half received only 1 dose. Sixteen percent and 3% respectively of

patients received mild and moderate analgesia. Although the efficacy of the analgesia was not determined, case summaries indicate undertreatment of pain. For example, despite Panado (6 hourly doses) and morphine (10 doses), nursing entries described a patient as 'Distressed+++. Still distressed+++. In HBO_2 but remains distressed' (Record 32). Use of mild and moderate analgesia failed to control the symptoms in a 31-month old child who according to the medical notes respectively was 'Flaring and recessing+++, visibly distressed' and 'Very distressed at night. Still very distressed'. (Record 46) These findings warrant an empirical approach to pain and symptom management in children with HIV/AIDS. Successful implementation of pain and symptom management depends on incorporating the assessment of pain into the overall care of each child during each contact.[39]

Whilst doctors may (unconvincingly) plead ignorance of pain and distress that is documented in the nursing notes only, they personally documented pain and distress in 13 patients yet failed to prescribe analgesia. Surely, observed and reported suffering begs an appropriate response from the caregiver. Even though a doctor may not be able to restore the health of a child, according to the RCPCH,[21] doctors have 'an absolute duty to comfort and to cherish the child and to prevent pain and suffering'. (p. 16)

The symbolic implication of morphine as a sign of 'giving up' may have deterred some clinicians from prescribing morphine, the more so since most patients were infants. Still, the most significant barrier among clinicians to administering adequate pain medication, especially morphine, is the fear of hastening death through respiratory depression, excess sedation or both. Alarmingly, Vazirani et al[118] found that as residents progress through their training they become less comfortable with administering pain medication to a dying child through fear of hastening death. Yet according to expert opinion[146] morphine, the most extensively studied, widely used and cheapest opiate available, is perfectly safe even for use in neonates. Arguably, the risk of undertreating pain and distress in the dying child should be of greater concern medically and morally than the risk of suppressing respiratory effort. If prolonging life is no longer in a child's best interests and promoting comfort is the primary goal, clinicians should not hesitate to use full and effective doses of pain medication, even if a possible secondary effect is sedation, depression of respiration and possible hastening of death.[96]

In these circumstances the ethical justification for aggressive palliation is the rule of double effect.[98] In keeping with the criteria for double effect reasoning, the use of morphine is itself not immoral as long as the doctor's intent is to relieve pain and not to cause death through respiratory depression even though it may be foreseeable that death may be hastened. If pain becomes severe in the terminal stage, double effect reasoning provides a defensible rationale for escalating doses of morphine for physicians who support neither euthanasia nor the practice of allowing patients to die with untreated suffering. Thus the rule of double effect allows clinicians to treat specific symptoms of dying patients even at the risk of hastening death.

Use of strong analgesia is also justified on grounds of the best interest standard.[96] According to this standard, the patient should receive treatment that provides the most benefit and the fewest burdens. Pain relief and symptom management should be provided because they relieve burdensome symptoms and therefore promote the dying patient's best interests. Pain and symptom relief is almost always in a child's best interests and should be the standard of care in the absence of strong and explicit indications to the contrary. (Emanuel)

Nurses play an extremely important role in the assessment of symptoms and the control of pain in dying children because they usually have the most frequent, continuous patient contact.

Nurses accounted for much of reported pain and distress in this study. It can only be speculated as to the extent of moral distress experienced by nurses unable to meet their moral obligations to maximise comfort through adequate management of patients' pain and discomfort. In 1997, almost two thirds of a sample of professional nurses at RXH reported having nursed a child they felt had been made to suffer unnecessarily.[51] At that time, 98% of respondents believed RXH needed a bioethics committee, perhaps in the vain hope it could offer expert second opinion. According to Rushton and colleagues, '...patient suffering often results in the suffering of caregivers themselves.'[147] (p.82) If this is so, adequate pain management would not only relieve patients' suffering but that of nurses as well. On the other hand, training in the use of non-pharmacological pain control measures, such as swaddling, non-nutritive sucking (dummy), massage and positioning would allow nurses to manage some of the discomfort themselves. Moreover, these interventions do not require skilled nursing and could be undertaken by less highly trained nursing personnel. Additionally professional bodies[47] recommend the availability of psychological support for the caregivers of dying children, an example of which might be routine individual or group counselling with a trained peer, social worker or psychologist.

In summary, of the 165 patients studied, only half were identified as dying and slightly more than 40% received a comfort care plan. This was far fewer than the number of patients with DNR orders. Patients also received their comfort care plans rather late in their terminal hospitalisations, especially long stay patients (16+ days). Moreover, the care received by patients with these plans was not fully consistent with a plan to institute only comfort measures, as indicated by frequent continued provision of IV therapies and diagnostic procedures. In some cases, the uncertainty of short-term prognoses for acutely ill children with progressive disease made a mixed management strategy appropriate. Overall, however, these patterns of decision making may represent a lack of clarity or ambivalence about the goals of care, habitual adherence to established hospital practice, concern about 'doing nothing' or a therapeutic disposition to maintain treatment in order to preserve life. The heterogeneity of care received by patients with comfort care plans may have reflected confusion among clinicians about use of vague terms such as 'comfort care' or 'supportive care' and a lack of a clear and coherent standard of practice for dying HIV/AIDS patients. Of great concern was the undertreatment and late treatment of pain and distress in almost half the patients, most likely explained by clinicians' fear of hastening death in such young patients.

In the final chapter, recommendations are offered to address shortcomings in the end of life care of children dying with HIV/AIDS.

Chapter 5: Summary of Main Findings and Key Recommendations

5.1 Summary of Main Findings

5.1.1 Clinical Characteristics

This study of hospital deaths among 165 HIV-infected children focused on 3 key decision making variables with distinctive clinical significance: presence of a DNR order, identification of the patient as dying, and comfort care plans. During the terminal hospitalisation, doctors had to make key decisions on gravely ill patients whose median age was 4 months and median length of stay was 6 days. The length of stay for three quarters of patients was less than 2 weeks and one quarter of patients died within 3 days of admission. The ELISA status of less than half the patients was known on admission and one third of patients fell in disease Category B. The intensity of diagnostic and therapeutic interventions received by many patients, particularly infants in disease Category B in the first week of admission, was dictated and justified on grounds of diagnostic and prognostic uncertainty, a high likelihood of PCP pneumonia which can be lethal, and treatment regimens whose efficacy requires prompt IV administration of medications over a minimum of several days. In many patients, the rapidity of deterioration, coupled with clinical uncertainty, likely made a decision to withdraw curative care in favour of palliative care difficult, despite the fact these children soon died. Since these patients face a substantial risk of death at any time during their hospitalisation and, in some, the fatal outcome cannot be anticipated in time to permit a pivotal shift from aggressive care to comfort care, the traditional dichotomy between curative care and palliative care needs to be replaced by a continuum of care in which both proceed together, regardless of outcome. For some patients neither a purely curative nor a purely palliative model of care is suitable. Instead, in the face of considerable clinical uncertainty, the most suitable model of care will reflect individual patients' needs and goals. Goals establish the rationale for treatment and should precede specific treatment decisions. If an intervention becomes more burdensome than beneficial given the overall goals of care, it should be limited or withdrawn.

5.1.2 Do Not Resuscitate Orders

Eighty four percent of patients had a DNR order. DNR orders meant patients were not subject to non-beneficial resuscitation and intensive care-based interventions, which might merely have prolonged dying. As importantly, DNR orders were not misinterpreted as implying no treatment, and patients continued to receive full medical treatment, such as IV therapies, short of resuscitation and ventilation. On the other hand, many patients with DNR orders were subject to extensive aggressive interventions, despite their status as patients expected to die imminently.

In many respects documentation and communication of DNR orders failed to comply with procedural and ethical requirements laid down in professional guidelines. DNR orders appeared simultaneously in only 41% of medical and nursing entries. Thus the resuscitation status of about two thirds of patients was not written in the nursing notes. In the event of a cardiac or respiratory arrest, and in the absence of a DNR order, nurses have a legal duty to offer full medical treatment including CPR to patients. Due to failed communication between doctors and nurses, many terminally ill children may have unnecessarily received highly invasive, burdensome interventions. Furthermore, in 39% and 63% respectively of folders, doctors failed to provide documentation of the justification for the DNR order or whether the DNR order had been discussed with parents. Not only does unilateral decision making ignore

parental values and preferences, it also disregards professional guidelines that stipulate parents as principal decision makers regarding treatment decisions for their children. Rarely is the question of whether or not to perform CPR a purely medical one. Inconsistent use of terminology in the DNR orders compounded the potential for miscommunication between doctors and nurses. The equivalent instruction, for example, 'Not for IPPV' or "Not for CPR' appeared in only 54% of matched medical and nursing notes. In the remainder, doctors and nurses recorded incompatible orders, variously restricting ventilation, CPR, ambubagging and inotropes. On busy hospital wards with rotating staff-in-training, it is ill advised to assume a shared understanding of these instructions, which imply limitation of different interventions. It can only be speculated whether miscommunication or failed documentation accounted for 7 episodes of resuscitation in patients with standing DNR orders.

Lack of a standardised approach in the medical notes as to where DNR orders are documented has the potential for confusion. DNR orders were written in front of medical notes, inside medical notes or in both locations. In a crisis doctors are likely to waste valuable time trying to locate a DNR order hidden somewhere inside daily progress notes. DNR orders need to appear prominently and consistently in one place in doctors' and nurses' notes.

5.1.3 Evidence of Dying

Using terminology such as terminally ill, poor prognosis and end stage, doctors identified 50% of patients as dying. This is surprisingly low considering that most DNR orders were justified on grounds of imminent death. It is possible doctors, reluctant to label patients as dying, preferred to use DNR orders as proxy measures of evidence of dying. On the other hand, some patients with no identifiable terminal phase will deteriorate rapidly despite maximal treatment. In the face of clinical uncertainty, much aggressive care will appear to have been non-beneficial only after death when the perspective is quite different.

Several explanations are offered to account for doctors' reluctance to label patients as terminal. Even in advanced disease, the clinical course of HIV/AIDS can be unpredictable and doctors may find it difficult to know with certainty if a patient is terminal. Whether further aggressive therapy is warranted in a seriously ill child is one of the most difficult decisions a clinician makes daily. Doctors may prefer to err on the side of biological life, and for some patients this will adversely affect the quality of dying. If parents are told their child is dying doctors worry they will lose hope. Yet systematically overoptimistic prognoses or failure to recognise a child is dying may lead to unrealistic expectations by parents and burdensome care at the end of life. Furthermore, knowledge of their child's prognosis may have increased the proportion (55%) of parents present at the bedside when their child died.

5.1.4 Comfort Care Plans

The low rate (44%) of comfort care plans, documented on average after 2 weeks' hospitalisation suggests doctors had difficulty making the transition from curative to palliative care. This ambivalence is illustrated by the incoherence of many plans, which included procedures and treatments neither meant for, nor likely to promote patients' comfort. Moreover, in 2 in 5 folders of patients with a comfort care plan there was no record of whether doctors had discussed the decision to change from curative care to palliative care with the family. A decision that the burdens of life-sustaining treatment outweigh the benefits is a non-medical determination of how valuable it is to continue living and the degree of a patient's suffering. Clearly doctors should not make these judgements independently, since they may

be influenced by their own professional, religious and sociological backgrounds. In line with legal, ethical and professional norms, parents are expected to make these decisions in partnership with the doctor, according to the best interests standard. Even if doctors feel stressed and ill equipped to initiate discussions regarding palliation, it does not justify their not doing it at all.

Whilst the presence of a comfort care plan significantly reduced the relative proportion of patients receiving IV therapies in their last 24 hours of life, 73% and 62% respectively of patients continued to receive IV fluids and IV antibiotics. Patients were twice as likely to receive intravenous than oral antibiotics. Some antibiotic drugs may promote comfort by reducing adverse symptoms caused by infection (1 in 4 children who died in the general wards experienced respiratory symptoms). However, if a patient has no distress from infection, antibiotics may only prolong dying and add to a patient's discomfort by requiring IV access. If continued use is justified, antibiotics should be administered orally rather than intravenously.

It has been difficult to convince health care professionals that there are times when it may be appropriate to withdraw artificial nutrition and hydration, despite ethical guidelines and court decisions that support the practice. Patients were 4 times as likely to receive nasogastric as opposed to oral feeds shortly before they died. Doctors' reluctance to withdraw artificial nutrition and hydration was underscored by the finding that 79% and 58% respectively of long stay patients (mean length of stay 29 days) with a comfort care plan received IV fluids and nasogastric feeds in their last 24 hours. Only 16% of these patients whose average age was 12 months received oral feeds. The emerging consensus is that dying patients experience little if any discomfort upon the withdrawal of tube feedings or IV hydration. On the contrary, continued treatment may cause considerable discomfort from fluid overload or if restraints are required. Accordingly, children who are imminently dying should receive oral rather than artificial nutrition and hydration. Oral feeding would increase interpersonal contact between children and mothers and nurses, and would reduce procedural pain associated with re-siting IV lines when they tissue. Decreased use of non-beneficial IV lines would also reduce the risk of needle stick injuries among junior medical staff who struggle to find veins in extremely wasted infants.

Head box oxygen administered to 38% of infants (median age 3 months) in their last 24 hours of life would have prevented parents holding their dying babies. Whilst increased use of nasal prong oxygen would give a parent more access to their child, the oxygen requirements of these terminal infants may have been higher than nasal prong oxygen could deliver. However, if morphine were optimally used, these infants may have been less distressed allowing the use of nasal prong oxygen, thereby giving parents more access to their dying child.

5.1.5 Paediatric Intensive Care

In light of inadequate outcome data from developing countries on survival rates of HIV-infected children discharged from intensive care units, it may have been appropriate that 23% of patients with apparently reversible illness were admitted to the PICU. Employing an individualised prognostic strategy, doctors initiated intensive care and carefully monitored a patient's clinical response to treatment. If a patient's clinical condition failed to improve treatment was withdrawn. Indeed ventilation was the intervention most commonly withdrawn from patients in this study. Furthermore, this approach recognises there is no intrinsic moral difference between performing an action and omitting an action. Fittingly, patients identified as dying in the PICU were more likely to be extubated. Withdrawal of intrusive machinery coupled

with adequate use of analgesia and sedation allowed these patients to die peacefully, often in their parents' arms. Thus, even in an intensive care setting, a smooth transition from cure to palliation was possible for some patients.

In the future it may become necessary to develop criteria for admission of HIV-infected children to the PICU because it is a costly and scarce resource and there are some children who are unlikely to benefit from this highly invasive intervention. Because of a perceived danger that HIV-infected children may be unfairly discriminated against, development and implementation of any policies to limit access to paediatric intensive care will need to follow an explicit, rational, fair and democratic process among all interested parties. A policy will need to reflect moral values acceptable to the community, detail the mechanisms by which the policy was developed and the signatories to its creation, articulate appellate mechanisms and be legally admissible.

5.1.6 Pain, Distress and Palliation

Findings show that documented pain and distress was not treated, was undertreated or was treated too late. Fifty five percent of patients who died in the general wards experienced pain and distress in their last 48 hours of life, yet overall only 38% of patients, including those who died in the PICU, received morphine in their last 24 hours. That 2 in 5 patients with a comfort care plan failed to receive any analgesia, despite documented pain and distress, is cause for grave concern. By the same token, it is unacceptable that 2 in 5 patients with a comfort care plan received their first dose of morphine within hours of dying, despite a 2-day history of discomfort. If achievement of the best quality of life and relief of pain and other symptoms are fundamental goals of palliative care, palliation failed in many patients with a comfort care plan.

Some dying patients may need increasingly large doses of analgesics to alleviate discomfort, which, in turn, if not carefully monitored, carries some risk of respiratory depression and hastening death. Arguably, the risk of undertreating pain and discomfort in a dying child should be of greater concern morally and medically than the risk of suppressing respiratory effort. If prolonging life is no longer in a child's best interests and promoting comfort is the primary goal, clinicians should not hesitate to use full and effective doses of analgesia, even if a possible secondary effect is sedation, respiratory depression and possible hastening of death. Double effect reasoning provides a defensible rationale for escalating doses of analgesia for clinicians who support neither euthanasia nor the practice of allowing patients to die with untreated suffering.

That only 38% and 2% respectively of families benefited from social work and religious intervention suggests the broader goals of palliative care, concerned with families' psychological, psychosocial and spiritual needs, are not being addressed. High work loads and staff shortages probably account for the low rate of social work intervention. RXH does not have its own pastoral counsellors. If families require pastoral counselling, they must use their own religious/spiritual advisors or request referral to the pastoral care service at Groote Schuur Hospital. In a crisis situation this arrangement may not have suited many families.

In conclusion, doctors find it difficult to know when and in what circumstances to withhold or withdraw life-sustaining treatment in HIV-infected children. They proceed in faltering stages, usually beginning with a DNR order and cautiously moving towards withdrawal of aggressive interventions. All too often, they never reach the stage of only palliating the dying child. Trained to cure, doctors find it hard to know when 'enough is enough'. Yet, even as a child approaches death, the ethical standard that guides decision making for doctors and parents

alike is the best interests of the child. No ethical principle supports continuation of invasive diagnostic and therapeutic interventions, which merely increase a child's suffering and prolong dying.

Once a doctor has decided a child will die soon, the doctor has implicitly determined that the benefits of a brief prolongation of an increasingly miserable, uncomfortable life outweigh the burdens of aggressive medical intervention. This provides the ethical justification for withholding not only CPR, but also other invasive interventions whose goal is cure, a medical goal that is no longer appropriate in the case of an imminently dying child. Even interventions that arguably provide some palliation, such as IV therapies, may be discontinued if the harm inflicted in their provision burdens an already suffering child, with little or no net benefit.

Once it becomes clear the child will soon die and a DNR order should be issued, there can be few instances where it is in the child's best interests to continue aggressive curative medical interventions. The presumption should be that, simultaneously with issuance of a DNR order, a decision should be made that discontinues or limits invasive, aggressive curative interventions, and substitutes a comfort care plan. The focus should shift decidedly from curative therapy and its burdens to only caring for the child. Moreover, if medically feasible and parents prefer, it may be more humane to allow the child to die at home.

Junior doctors with little experience and even less authority often face the above dilemmas. Therefore, hospitals should be encouraged to adopt protocols or policies that assist doctors make these hard decisions. Such policies would provide medically valid and ethically legitimate criteria that help determine when and under what circumstances a doctor should issue a DNR order or terminate curative interventions that are no longer in the interests of the child. In addition, a policy would outline procedures to be followed in reaching these decisions.

5.2 Limitations of Study

It is necessary to consider these findings against certain limitations in the study:

I. The findings are limited by problems inherent in retrospective chart review, in particular the quality of medical record keeping and the extent of missing data.[148] This study was limited to documented decisions regarding end of life care. A good proportion of decision making is undocumented. Furthermore, documentation by doctors and nurses may not have been optimal in times of stress and crisis. Conversely, care may have been recorded but not provided.[149]

II. It was not possible to capture the complexity of factors that affected end of life decision making. Nor, from a retrospective record review, was it possible to accurately determine the frequency of decisions not to pursue a potentially life-saving therapy. Arguably, a decision to withdraw a current therapy is a definitive decision with practical and often immediate consequences. On the other hand, discussion about withholding therapies in the future is a hypothetical matter. The patient may never require a particular intervention and doctors' intentions regarding what therapies they might withhold are, in the absence of procedure-specific DNR orders, unlikely to have been recorded.

III. Record review can reveal only the viewpoint of doctors and nurses. It does not include the views of families concerning end of life care. Future research needs to address parental attitudes and satisfaction with end of life care. The impact of culture on end of

life decision making also needs investigation. Likewise future research needs to consider views of hospital management regarding the development of policies on terminal care.

IV. The study was limited to children who died in a single, specialised teaching institution, and findings may not be generalisable to other hospitals. It is possible practices will differ in community hospitals.

V. The study examined patients' terminal hospitalisation. It can only be speculated if hospitalisation could have been avoided by greater availability of palliative or home-based care in the community. Issues relating to home-based care for HIV-infected children were beyond the scope of this hospital-based study.

VI. The ethical reasoning for treatment limitations was difficult to assess in a retrospective study – only rationales that were documented in the medical record were identified. Reasons to discontinue support such as quality of life assessments may not have been documented because of their subjective nature or concern over medical/legal liability. Likewise, doctors may have been reluctant to document decisions based on resource allocation considerations.

VII. The presence of pain and distress in patients was determined by the researcher's subjective interpretation of documented symptomatology. For example, clinicians may dispute the interpretation of expressions such as 'recessing+++' as evidence of dyspnoea. Against this it is argued that nurses' and doctors' repeated description of patients as displaying these symptoms despite use of oxygen therapies and analgesia reasonably indicated patients' discomfort.

5.3 Key Recommendations

5.3.1 Improvements at the Bedside

In light of the findings that 84% of patients had DNR orders, 50% were identified as dying and 44% had a comfort care plan, it is recommended that at the bedside:

- Clinicians strive to increase the proportion of patients identified as dying and the proportion of comfort care plans to more closely approximate the proportion of DNR orders.
- Clinicians make more timely decisions so that patients who have DNR orders are identified as dying and receive comfort care plans earlier in the course of hospitalisation. Timely end of life decision making is particularly important among long stay patients.
- Clinicians strive to increase the proportion of imminently dying patients who are appropriately withdrawn from non-beneficial life-sustaining treatments.
- Comfort care plans are more coherent so dying patients receive only treatments that will promote comfort.
- Clinicians and nurses make pain and discomfort a fifth vital sign, requiring routine monitoring along with pulse, blood pressure, respirations and heart rate.

5.3.2 Improvements in Institutional Practice

Data on the frequency, sequence and coherence of end of life decisions in particular comfort care plans corroborate the need for institutional reforms to better integrate palliative care into mainstream hospital practice. To achieve better outcomes, it will be necessary to improve practice patterns formulated at an institutional level, rather than rely only on enhanced decision making at the bedside. Thus clinicians would benefit from a directed process that would help them plan more timely, comprehensive and coherent end of life care. To this end, it is

recommended hospitals develop guidelines for treatment limitation decisions and a medical treatment plan (Care Plan) to discern and negotiate goals of care and manage appropriate transitions from life-sustaining treatment to palliation. A structured Care Plan would be appropriate for all HIV-infected patients across the continuum of care including those requiring aggressive, curative-based care, palliative care or a mixed management approach. Whilst some elements of the care plan will not be immediately appropriate to every individual patient, such a plan would prompt clinicians to think about palliative interventions and supportive services among patients still receiving curative-based care. Additionally, it would go some way to dispel negative connotations that care plans set limits but not standards of care for dying patients. A structured approach might also reduce ambiguity and miscommunication within the health care team. Determination of the format and content of a Care Plan will need the participation of all interested parties involved in the management of hospitalised terminally ill children with HIV/AIDS.

Elements of a Care Plan should describe, among others:

- patient's clinical condition
- prognosis
- goals of care (cure, prolong life, comfort/palliation, mixed)
- intended level of medical intervention, including DNR status
- therapies to be instituted or continued
- existing diagnostic and therapeutic therapies to be withdrawn and the order in which this will be done
- family's awareness and understanding of the plan, and their preferences regarding end of life decisions
- availability of family support, including contact telephone numbers
- cultural, psychosocial and spiritual issues
- planned interventions for social work or pastoral care
- review of symptoms (for example, pain, shortness of breath, anxiety, excessive crying or irritability)
- prescribed palliative treatments and degree of symptomatic relief

The initial implementation of a Care Plan will need rigorous monitoring and evaluation before it becomes part of a formal hospital policy on end of life care for children with HIV/AIDS. In similar vein, a Care Plan will be a dynamic document, requiring ongoing re-evaluation, as it responds to changing patient, professional and institutional needs. In addition to expanding options for patient care, a structured Care Plan will provide a model to help medical students and junior staff address end of life issues comprehensively. Critics repeatedly cite deficiencies in this aspect of clinical education. Finally, the Care Plan would provide an opportunity to instruct trainees in pain management and other palliative care techniques.

References

1. Schroeder SA. The legacy of SUPPORT. *Ann Intern Med* 1999; **131**: 780-1.
2. Donaldson MS, Field MJ. Measuring quality of care at the end of life. *Arch Intern Med* 1998; **158**: 121-8.
3. Morrison RS, Siu AL, Leipzig RM, Cassel CK, Meier DE. The hard task of improving the quality of care at the end of life. *Arch Intern Med* 2000; **160**: 743-7.
4. Lo B, Snyder S, Sox HC. Care at the end of life. *Ann Intern Med* 1999; **130**: 772-4.
5. McPhee SJ, Rabow MW, Pantilat SZ, Winker MA. Finding our way - perspectives on care at the close of life. *JAMA* 2000; **284**: 2512-3.
6. Hirschfeld S, Moss H, Dragisic K, Smith W, Pizzo PA. Pain in pediatric human immunodeficiency virus infection: incidence and characteristics in a single-institution pilot study. *Pediatrics* 1996; **98**: 449-52.
7. Ljungman G, Gordh T, Sorenson S, Kreuger A. Pain in paediatric oncology: interviews with children, adolescents and their parents. *Acta Paediatr* 1999; **88**: 623-30.
8. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000; **342**: 326-33.
9. Robinson WM, Ravilly S, Berde C, Wohl ME. End-of-life care in cystic fibrosis. *Pediatrics* 1997; **100**: 205-9.
10. Parker D, Maddocks I, Stern LM. The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy. *J Paediatr Child Health* 1999; **35**: 245-50.
11. Nelson LJ, Nelson RM. Ethics and the provision of futile, harmful, or burdensome treatment to children. *Crit Care Med* 1992; **20**: 427-33.
12. Fleischman AR, Nolan K, Dubler NN, et al. Caring for gravely ill children. *Pediatrics* 1994; **94**: 433-9.
13. Rhoden NK. Treating Baby Doe: the ethics of uncertainty. *Hastings Cent Rep* 1986; **16** (Aug): 34-42.
14. Lantos JD, Tyson JE, Allen A, et al. Withholding and withdrawing life sustaining treatment in neonatal intensive care: issues for the 1990s. *Arch Dis Child* 1994; **71**: F218-F223.
15. Nelson LJ, Rushton CH, Cranford RE, Nelson RM, Glover JJ, Truog RD. Forgoing medically provided nutrition and hydration in pediatric patients. *J Law Med Ethics* 1995; **23**: 33-46.
16. Burns JP, Truog RD. Ethical controversies in pediatric critical care. *New Horiz* 1997; **5**: 72-84.
17. Ashwal S, Bale JF, Coulter DL, et al. The persistent vegetative state in children: report of the Child Neurology Society Ethics Committee. *Annal Neurol* 1992; **32**: 570-6.
18. American Academy of Pediatrics. Guidelines for forgoing life-sustaining medical treatment. *Pediatrics* 1994; **93**: 532-6.
19. American Academy of Pediatrics. The initiation and withdrawal of treatment for high-risk newborns. *Pediatrics* 1995; **96**: 362-3.
20. American Academy of Pediatrics. Ethics and the care of critically ill infants and children. *Pediatrics* 1996; **98**: 149-52.
21. Royal College of Paediatrics and Child Health. Withholding or withdrawing life saving treatment in children. A framework for practice. RCPCH, London, 1997.
22. McHaffie HE, Cuttini M, Brolz-Voit, et al. Withholding/withdrawing treatment from neonates: legislation and official guidelines across Europe. *J Med Ethics* 1999; **25**: 440-6.

23. Masera G, Spinetta JJ, Jankovic M, et al. Guidelines for assistance to terminally ill children with cancer: a report of the SIOP working committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol* 1999; **32**: 44-8.
24. Doyal L, Larcher VF. Drafting guidelines for the withholding or withdrawing of life sustaining treatment in critically ill children and neonates. *Arch Dis Child Neonatal Ed* 2000; **83**: F60-F63.
25. Cuttini M, Nadai M, Kaminski M et al. End-life-decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *Lancet* 2000; **355**: 2112-8.
26. Kollee LAA, van der Heide A, de Leeuw R, van der Maas PJ, van der Wal G. End-of-life decisions in neonates. *Semin Perinatol* 1999; **23**: 245-50.
27. Mink RB, Pollack MM. Resuscitation and withdrawal of therapy in pediatric intensive care. *Pediatrics* 1992; **89**: 961-3.
28. Lantos JD, Berger BA, Zucker AR. Do-not-resuscitate orders in a children's hospital. *Crit Care Med* 1993; **21**: 52-5.
29. Ryan CA, Byrne P, Kuhn S, Tyebkhan J. No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *J Pediatr* 1993; **123**: 534-8.
30. Leveton M, Pollack MM, Cuerdon TT, Ruttimann UE, Glover JJ. Limitations and withdrawals of medical intervention in pediatric critical care. *JAMA* 1994; **272**: 1271-5.
31. Balfour-Lynn IM, Tasker RC. Futility and death in paediatric medical intensive care. *J Med Ethics* 1996; **22**: 279-81.
32. Martinot A, Grandbastien B, Leteutre S, Duhamel A, Leclerc F. No resuscitation orders and withdrawal of therapy in French paediatric intensive care units. *Acta Paediatr* 1998; **87**: 769-73.
33. Goh AYT, Lum LCS, Chan PWK, Bakar F, Chong BO. Withdrawal and limitation of life support in paediatric intensive care. *Arch Dis Child* 1999; **80**: 424-8.
34. Van der Wal ME, Renfurm LN, Gemke RJBJ. Circumstances of dying in hopsitalized children. *Eur J Pediatr* 1999; **158**: 560-5.
35. McCallum DE, Byrne P, Bruera E. How children die in hospital. *J Pain Symptom Manage* 2000; **20**: 417-23.
36. Rubenstein JS, Unti SM, Winter RJ. Pediatric resident attitudes about technologic support of vegetative patients and the effects of parental input – a longitudinal study. *Pediatrics* 1994; **94**: 8-12.
37. Levin BW, Krantz DH, Driscol JM, Fleischman AR. The treatment of non-HIV-related conditions in newborns at risk for HIV: a survey of neonatologists. *Amer J Pub Health* 1995; **85**: 1507-13.
38. Randolph AG, Zollo MB, Egger MJ, Guyatt GH, Nelson RM, Stidham GL. Variability in physician opinion on limiting pediatric life support. *Pediatrics* 1999; **103**: 897-8 (e46 Abstract).
39. Wishnie E, Weisman SJ. Children with AIDS - pain syndromes and unique issues of assessment and management. *Child Adolesc Psychiatr Clin Am* 1997; **6**: 863-78.
40. Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals. *Arch Intern Med* 1996; **156**: 2130-6.
41. Asch DA, Faber-Langendoen K, Shea JA, Christakis NA. The sequence of withdrawing life-sustaining treatment from patients. *Am J Med* 1999; **107**: 153-6.
42. Asch DA, Christakis NA. Why do physicians prefer to withdraw some forms of life support over others? *Med Care* 1996; **34**: 103-11.
43. Christakis NA. Biases in how physicians choose to withdraw life support. *Lancet* 1993; **342**: 642-6.

44. Keenan HT, Diekema DS, O'Rourke P, Cummings P, Woodrum DE. Attitudes toward limitation of support in a pediatric intensive care unit. *Crit Care Med* 2000; **28**: 1590-4.
45. Report of a Joint Working Party of the Association for Children with Life-Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. A guide to the development of children's palliative care services. Association for Children with Life-Threatening or Terminal Conditions and their Families and RCPCH, London, 1997.
46. American Academy of Pediatrics and Canadian Paediatric Society. Prevention and management of pain and stress in the neonate. *Pediatrics* 2000; **105**: 454-61.
47. American Academy of Pediatrics. Palliative care for children. *Pediatrics* 2000; **106**: 351-7.
48. Anand KJS and the International Evidence-based Group for Neonatal Pain. *Arch Pediatr Adolesc Med* 2001; **155**; 173-80.
49. Turner JS, Michell WL, Morgan CJ, Benatar SR. Limitation of life support: frequency and practice in a London and a Cape Town intensive care unit. *Intensive Care Med* 1996; **22**: 1020-5.
50. Wainer S, Khuzwayo H. Attitudes of mothers, doctors, and nurses toward neonatal intensive care in a developing country. *Pediatrics* 1993; **91**: 1171-5.
51. Bingham T, Herman C. Professional nurses' perceptions at Red Cross War Memorial Children's Hospital concerning ethics and ethical dilemmas [dissertation]. Cape Town: University of Cape Town; 1997.
52. Lynn J, Arkes HR, Stevens M et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. *J Amer Geriat Soc* 2000; **48**: S214-21.
53. Westwood ATR. Childhood deaths due to HIV - the role of the new death certificate. *S Afr Med J* 2000; **90**: 877-8.
54. Fins JJ, Miller FG, Acres CA, Bacchetta MD, Huzzard LL, Rapkin BD. End-of life decision-making in the hospital: current practice and future prospects. *J Pain Symptom Manage* 1999; **17**: 6-15.
55. Centers for Disease Control and Prevention. 1994 revised classification system for human immunodeficiency virus infection in children less than 13 years of age. *MMWR* 1994; **43**: 1-19.
56. Aldrovandi GM. Natural history of pediatric disease. In: Zeichner SI, Read JSR. Editors. Handbook of pediatric HIV care. Philadelphia: Lippincott Williams & Wilkins; 1999. p.77-138.
57. Hussey GD, Reijnhart RM, Sebens AM, Burgess J, Schaaf S, Potgieter S. Survival of children in Cape Town known to be vertically infected with HIV-1. *S Afr Med J* 1998; **88**: 554-8.
58. Smith R. A good death. *BMJ* 2000; **320**: 129-30.
59. American Academy of Pediatrics and Society of Critical Care Medicine. Guidelines for developing admission and discharge policies for the pediatric intensive care unit. *Pediatrics* 1999; **103**: 840-2.
60. The Ethics Committee of the Society of Critical Care Medicine. Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly inadvisable treatments. *Crit Care Med* 1997; **25**: 887-91.
61. Oates L. The court's role in decisions about medical treatment. *BMJ* 2000; **321**: 1282-4.
62. Benatar SR, Abels C, Abratt R, et al. Statement on withholding and withdrawing life-sustaining therapy. *S Afr Med J* 1994; **84**: 254-6.
63. South African Law Commission. Project 86: Report on Euthanasia and the Artificial Preservation of Life. Pretoria, South Africa, 1999.

64. Landman WA, Henley LD. Legalising advance directives in South Africa. *S Afr Med J* 2000; **90**: 785-7.
65. Doyal L, Wilsher D. Withholding cardiopulmonary resuscitation: proposals for formal guidelines. *BMJ* 1993; **306**: 1593-6.
66. Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics. 4th Edition. New York: McGraw-Hill Health Professions Division; 1998.
67. Sulmasy DP, Geller G, Faden R, Levin DM. The quality of mercy: caring for patients with "do not resuscitate" orders. *JAMA* 1992; **267**: 682-6.
68. Mittelberger JA, Lo B, Martin D, Uhlmann RF. Impact of a procedure-specific do not resuscitate order form on documentation of do not resuscitate orders. *Arch Intern Med* 1993; **153**: 228-32.
69. O'Toole EE, Youngner SJ, Juknialis BW, Daly B, Bartlett ET, Landefeld CS. Evaluation of a treatment limitation policy with a specific treatment-limiting order page. *Arch Intern Med* 1994; **154**: 425-32.
70. Heffner JE, Barbieri C, Casey K. Procedure-specific do-not-resuscitate orders. *Arch Intern Med* 1996; **156**: 793-7.
71. Heffner JE, Barbieri C, Fracica P, Brown LK. Communicating do-not-resuscitate orders with a computer-based system. *Arch Intern Med* 1998; **158**: 1090-5.
72. Jacobson JA, Kasworm E. May I take your order: a user-friendly resuscitation status and medical treatment plan form. *Quality Management in Health Care* 1999; **7**; 13-20.
73. Veatch RM. Death, dying and the biological revolution. New Haven: Yale University Press; 1989. p. 59-88.
74. Meisel A, Snyder L, Quill T. Seven legal barriers to end-of-life care. *JAMA* 2000; **284**: 2495-2501.
75. The Society of Critical Care Medicine Ethics Committee. Attitudes of critical care medicine professionals concerning forgoing life-sustaining treatments. *Crit Care Med* 1992; **20**: 320-6.
76. Solomon MZ, O'Donnell LO, Jennings B, et al. Decisions near the end of life: professional views on life-sustaining treatments. *Amer J Pub Health* 1993; **83**: 14-23.
77. Caralis PV, Hammond JS. Attitudes of medical students, housestaff, and faculty physicians toward euthanasia and termination of life-sustaining treatment. *Crit Care Med* 1992; **20**: 683-90.
78. Dickenson DL. Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life. *J Med Ethics* 2000; **26**: 254-60.
79. Rebagliato M, Cuttini M, Broggin L, et al. Neonatal end-of-life decision making. *JAMA* 2000; **284**: 2451-59.
80. Childress JF. When is it morally justifiable to discontinue medical nutrition and hydration? In: Childress JF. Practical reasoning in bioethics. Bloomington: Indiana University Press; 1997. p.152-66.
81. Ravenscroft AJ, Bell MDD. 'End-of-life' decision making within intensive care - objective, consistent, defensible? *J Med Ethics* 2000; **26**: 435-40.
82. Miraie ED. Withholding nutrition from seriously ill newborn infants: a parent's perspective. J Pediatr 1988; 113: 262-5.
83. Mitchell I, Nakielna E, Tullis E, Adair C. Cystic fibrosis - end stage care in Canada. *Chest* 2000; **118**: 80-4.
84. Meert KL, Thurston C, Sarnaik AP. End-of-life decision-,making and satisfaction with care: parental perspectives. *Pediatr Crit Care Med* 2000; **1**: 179-85.
85. Hilden JM, Emanuel EJ, Fairclough DL et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 2001; **19**: 205-12.

86. Leveton M. Palliative care in the intensive care unit. New Horiz 1998; **6**: 383-97.
87. Goldman A. ABC of palliative care: special problems of children. *BMJ* 1998; **316**: 49-52.
88. Frager G. Palliative care and terminal care of children. *Child Adolesc Psychiatr Clin Am 1997*: **6**: 889-909.
89. Oleske JM, Czarniecki L. Continuum of palliative care: lessons from caring for children infected with HIV-1. *Lancet* 1999; **354**: 1287-91.
90. Royal College of Paediatrics and Child Health. Prevention and control of pain in children. London: BMJ Publishing Group, 1997.
91. Leith PJ, Weisman SJ. The management of painful procedures in children. *Child Adolesc Psychiatr Clin Am* 1997: **6**:829-42.
92. Krauss B, Green SM. Primary care: sedation and analgesia for procedures in children. *N Eng J Med* 2000; **342**: 938-45.
93. Abu-Saad HH, Bours Gjj, Stevens B, Hamers JPH. Assessment of pain in the neonate. *Semin Perinatol* 1998; **22**: 402-16.
94. Southall DP, Burr S, Smith RD et al. The Child-Friendly Healthcare Initiative (CHFI): healthcare provision in accordance with the UN Convention on the Rights of the Child. *Pediatrics* 2000; **106**: 1054-64.
95. Schecter NL, Allen D. Physicians' attitudes toward pain in children. *J Devel Behav Pediatr* 1986; 6: 350-4.
96. Wolfe J. Suffering in children at the end of life: recognising an ethical duty to palliate. *J Clin Ethics* 2000; **11**: 157-63.
97. Thorns A, Sykes N. Opioid use in the last week of life and implications for end-of-life decision-making. Lancet 2000; 356: 398-9.
98. Sulmasy DP, Pellegrino ED. The rule of double effect. *Arch Intern Med* 1999; **159**: 545-50.
99. Quill TE, Dresser R, Brock DW. The rule of double effect - a critique of its role in end-of-life decision making. *N Eng J Med* 1997; **337**: 1768-71.
100. Doyal L. The moral character of clinicians or the best interests of patients? *BMJ* 1999; **318**: 1432-3.
101. Emanuel EJ. Pain and symptom control. *Hematol Oncol Clin North Am* 1996; **10**: 41-56.
102. Latimer EJ. Ethical care at the end of life. *CAMJ* 1998; **158**: 1741-7.
103. Ravilly S, Robinson W, Suresh S, Wohl ME, Berde CB. Chronic pain in cystic fibrosis. *Pediatrics* 1996; **98**: 741-7.
104. Czarniecki LM, Boland M, Oleske JM. Pain in children with HIV disease. *PAAC Notes* 1993; **5**: 492-5.
105. Anand A, Carmosino L, Glatt AE. Management of recalcitrant pain in a pediatric acquired immunodeficiency syndrome patient. *Pediatr Infect Dis* J 1993; **12**: 159-60.
106. Liben S. Pediatric palliative medicine: obstacles to overcome. *J Palliat Care* 1996; **12**: 24-8.
107. McGrath PJ. Attitudes and beliefs about medication and pain management in children. *J Palliat Care* 1996; **12**: 46-9.
108. Ruddick W. Do doctors undertreat pain? *Bioethics* 1996; **11**: 246-55.
109. Walco GA, Cassidy RC, Schecter NL. Pain, hurt, harm. *N Eng J Med* 1994; **331**: 541-4.
110. Breibart W, Kaim M, Rosenfeld B. Clinicians' perceptions of barriers to pain management in AIDS. *J Pain Symptom Manage* 1999; **18**: 203-212.
111. Porter FL, Wolf CM, Gold J, Lotsoff D, Miller JP. Pain and pain management in newborn infants: a survey of physicians and nurses. *Pediatrics* 1997; **100**: 626-32.

112. Cote CJ, Karl HW, Notterman DA, Weinberg JA, McCloskey C. Adverse sedation events in pediatrics: analysis of medications used for sedation. *Pediatrics* 2000; **106**: 633-44.
113. Wolfe J, Klar N, Grier HE et al. Understanding of prognosis among parents of children who died of cancer. *JAMA* 2000; **284**: 2469-75.
114. Billings JA, Block S. Palliative care in undergraduate medical education. *JAMA* 1997; **278**: 733-8.
115. Weissman DE, Block SD, Blank L, et al. Recommendations for incorporating palliative care education into the acute care hospital setting. *Acad Med* 1999; **74**: 871-7.
116. Danis M, Federman D, Fins JJ et al. Incoporating palliative care into critical care education: principles, challenges, and opportunities. *Crit Care Med* 1999; **27**: 2005-13.
117. Khaneja S, Milrod B. Educational needs among pediatricians regarding caring for terminally ill children. *Arch Peditar Adolesc Med* 1998; **152**: 909-14.
118. Vazirani RM, Slavin SJ, Feldman JD. Longitudinal study of pediatric house officers' attitudes toward death and dying. *Crit Care Med* 2000; **28**: 3740-45.
119. Sahler OJZ, Frager G, Leveton M, Cohn FG, Lipson MA. Medical education about end-of-life care in the pediatric setting: principles, challenges, and opportunities. *Pediatrics* 2000; **105**: 575-84.
120. Department of National Health and Population Development. Ninth annual national HIV survey of women attending antenatal clinics, October/November 1999. *Epidemiological Comments* 1999; **26**.
121. Zwi KJ, Pettifor JM, Soderlund N. Paediatric hospital admissions at a South African urban regional hospital: the impact of HIV, 1992-1997. *Annal Trop Paediatric* 1999; **19**: 135-42.
122. Yeung S, Wilkinson D, Escott S, Gilks CF. Paediatric HIV infection in a rural South African district hospital. *J Trop Pediatr* 2000; **46**: 107-10.
123. Roux P, Henley L, Cotton M, Eley B and the Paediatric HIV Census Group. Burden and cost of inpatient care for HIV-positive paediatric patients - status in the Cape Town metropole during the second week of March 1999. *S Afr Med J* 2000; **90**: 1008-1011.
124. Stucky C. Death watch in a ward once filled with laughter. The Sunday Independent 2001 Jan 14; p. 4 (col. 1-3).
125. Jeena PM, Coovadia HM, Bhagwanjee S. Prospective, controlled study of the outcome of human immunodeficiency virus-1 antibody-positive children admitted to an intensive care unit. *Crit Care Med* 1996; **24**: 963-7.
126. Bobat R, Coovadia H, Moodley D, Coutsoudis A. Mortality in a cohort of children born to HIV-1 infected women from Durban, South Africa. *S Afr Med J* 1999; **89**: 646-8.
127. Tudor-Williams G. HIV infection in children in developing countries. *Trans R Soc Trop Med Hyg* 2000; **94**: 3-4.
128. Bye MR. Human immunodeficiency virus infections and the respiratory system in children. *Pediatr Pulmonol* 1995; **19**: 231-42.
129. Galli L, de Martino M, Tovo PA, Gabiano C, Zappa M. Predictive value of the HIV paediatric classification system for the long-term course of perinatally infected children. *Int J Epidemiol* 2000; **29**: 573-8.
130. LaPuma J, Silverstein MD, Stocking CB, Roland D, Siegler M. Life-sustaining treatment: a prospective study of patients with DNR orders in a teaching hospital. *Arch Intern Med* 1988; **148**: 2193-8.
131. Sulmasy DP. Do patients die because they have DNR orders, or do they have DNR orders because they are going to die? *Med Care* 1999; **37**: 719-21.
132. Klein M, Zar H. ICU outcome in HIV-associated pneumonia - puzzles and hidden messages. *S Afr Med J* 1998; **88**: 1438-40.

133. Landman WA, Henley LD. Equitable rationing of highly specialised health care services for children: a perspective from South Africa. *J Med Ethics* 1999; **25**: 224-9.
134. Uhlmann RF, Cassel CK, McDonald WJ. Some treatment-withholding implications of no-code orders in an academic hospital. *Crit Care Med* 1984; **12**: 879-81.
135. Faber-Langendoen K. The clinical management of dying patients receiving mechanical ventilation. *Chest* 1994; **106**: 880-8.
136. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med* 1998; **158**: 2389-95.
137. Flaming D. Improve care and comfort: use the label 'dying'. *J Palliat Care* 2000; **16**: 30-6.
138. Davies B, Steele R. Challenges in identifying children for palliative care. *J Palliat Care* 1996; **12**: 5-8.
139. Klessig J. The effect of values and culture on life-support decisions. *West J Med* 1992; **157**: 316-22.
140. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000; **320**: 469-73.
141. Fox E. Predominance of the curative model of medical care. *JAMA* 1997; **278**: 761-3.
142. Czarniecki L. Advanced HIV disease in children. *Nurs Clin North Am* 1996; **31**: 207-19.
143. Bruera E, Neumann CM. Management of specific symptom complexes in patients receiving palliative care. *CMAJ* 1998; **158**: 1717-26.
144. Lo B, Dornbrand L. Guiding the hand that feeds. *N Eng J Med* 1984; **311**: 402-4.
145. Strong C. Can fluids and electrolytes be 'extraordinary' treatment? *J Med Ethics* 1981; **7**: 83-5.
146. James I, Scuplak S. Analgesia and sedation. In: Macnab A, Macrae D, Henning R, editors. Care of the critically ill child. London: Churchill Livingstone, 1999. p. 432-46.
147. Rushton CH, Hogue EE, Billett CA, Chapman K, Greenberg-Friedman D, Joyner M. End of life care for infants with AIDS: ethical and legal issues. *Pediatric Nursing* 1993; **19**: 79-83.
148. Sulmasy DP, Dwyer M, Marx E. Do the ward notes reflect the quality of end-of-life care? *J Med Ethics* 1996; **22**: 344-8.
149. Luck J, Peabody JW, Dresselhaus TR, Lee M, Glassman P. How well does chart abstraction measure quality? A prospective comparison of standardized patients with the medical record. *Am J Med* 2000; **108**: 642-9.

Appendix 1: Questionnaire

AUDIT OF DYING IN RED CROSS CHILDREN'S HOSPITAL

HIV Severity A B C Sex RECORD No.

Birth date Admission date Death date

Time of death Length of Stay (d) Age at death (m)

Elisa known on admission Y N

Place of death General ICU

ICU ADMISSION: Y N Direct Transfer

Reason for admission:

Transfer out (date) Length of Stay in ICU (d) Transfer out to death (d)

Comments on ICU Admission

RESUSCITATION: Y N CPR (date)

CPR location General ICU

CPR outcome: survived failed CPR to death (d)

CPR before Elisa result Y N Time of CPR

EVIDENCE of DYING: Y N 1st evidence of dying (date)

Admission to evidence (d) Evidence to death (d)

Verbatim Evidence of Dying:

DNR: Y N Date of DNR:

Admission to DNR (d) DNR to death (d)

DNR in progress notes of:

Doctors Y N Nurses Y N Front of Folder Y N

Verbatim DNR order in medical notes:

Verbatim DNR order in nursing notes:

Rationale for DNR: Y N If yes, specify:

Discussed DNR with: mother father other no record

COMFORT CARE PLAN: Y N

Date CCP Admission to CCP (d) CCP to death (d)

Discussed CCP with: mother father other no record

Verbatim Comfort Care Plan:

MORPHINE: Y N Method of delivery: Oral IV

Dose: Bolus PRN 4/6 hourly Continuous

Date of first dose: Admission to 1st dose (d) 1st dose to death (d)

Morphine given in: general ward ICU

INTERVENTIONS IN LAST 24 HOURS of LIFE

Oral feeds N-G feeds N-G tube Nebs NPO_2 HBO_2 Bloods X-rays

CPR Inotropes Ventilation Transfusion Intubation Extubation

Ringers Lactate Muscle relaxants A line CVP TPN Physiotherapy

Oral antibiotics IV antibiotics IV fluids Nystatin Steroids Panado

Anticonvulsants Morphine Sedation Anxiolytics

Other:

Documentation of treatment withdrawal/ withholding: Y N Date:

Location: General ICU Withdrawal to death (d)
Specify:

EVIDENCE of PAIN and DISTRESS in LAST 48 HOURS of LIFE

SYMPTOMS (presence of medical problems expected to cause pain):

In medical notes:

In nursing notes:

Mother at bedside at time of death: Y N no record

Other:

SOCIAL WORK: Y N No. SW visits

Reasons for SW Visit:

ADDITIONAL COMMENTS:

Appendix 2
Verbatim Rationales for DNR Orders (N=85)

Rationale	No.
AIDS with fulminating pneumonia.	1
AIDS with PCP pneumonia, already on maximal treatment.	1
AIDS with cardiac failure.	1
AIDS with extensive pneumonia, presumed pseudomonas.	1
AIDS with fulminating, progressive pneumococcal septicaemia and encephalopathy.	1
AIDS with presumed intracranial pressure. Unresponsive. Comatose.	1
AIDS with progressive deterioration.	2
AIDS with progressive pneumonia and hypoxia.	1
AIDS with progressively worsening pneumonia.	1
AIDS with rapid deterioration.	1
AIDS with recurrent diarrhoea, pseudomonas septicaemia and protein losing enteropathy.	1
AIDS with severe disease and cachexia.	1
AIDS with marrow suppression and progressive deteriorating pneumonia.	1
AIDS with severe pneumonia associated with hypoxia.	1
AIDS. Chest condition poor and unlikely to improve.	1
AIDS. Gravely ill.	1
Advanced AIDS.	2
Advanced AIDS with chronic lung disease.	3
Advanced AIDS with recurrent admissions. Now severe pneumonia.	1
Advanced AIDS. Septicaemia (staph) and progressive disease not responsive to treatment.	1
Brain death. AIDS. Equipment failure.	1
Category C disease.	1
Category C disease. Poor clinical condition and biochemistry.	1
Category C disease with progressive pneumonia and interstitial infiltrates, candidiasis, hepatomegaly, generalised lymphadonopathy, and progressive weight loss over 2 weeks.	1
Category C disease. Not improving.	1
Category C disease. End stage.	1
Clinical AIDS. Poor response to treatment for pneumonia.	1
Clinical AIDS with severe pneumonia.	1
Clinical AIDS. Now septicaemia and progressive pneumonia.	1
End stage AIDS.	6
Futile treatment not in interests of the child. Not improving despite the best we can do.	1
Futility. IPPV not justified.	1
HIV+ve early onset, severe wasting <60% expected weight and severe pneumonia.	1
HIV+ve not for ventilation but continue full ICU care.	1
HIV+ve on maximal antibiotic and medical treatment.	1
HIV+ve with e coli septicaemia and prolonged seizures.	1
HIV+ve with early onset disease. Worsening pneumonia despite treatment.	1
HIV+ve with early onset symptoms, severe pneumonia and hypoxia.	1
HIV+ve with severe recurrent pneumonia.	1
HIV+ve, PCP+ve, deterioration in respiratory function with full IV therapy.	1
HIV+ve, chest X-ray showing diffuse infiltrates.	1
HIV+ve, extensive candiida, neutropenia, progressive pneumonia on maximal antibiotic therapy.	1
HIV+ve, severe FFT and wasting, severe pneumonia, huge abscess on the head, status epilepticus and severe gastro.	1
HIV+ve with ongoing diarrhoea. Wasted+++. PCP pneumonia.	1
Moribund.	1
No improvement despite full treatment for PCP and associated lower respiratory tract infection.	1
No improvement despite maximal treatment.	1
No improvement despite maximal treatment for bacterial pneumonia.	1
Not improving.	1
Not improving. On maximal treatment for PCP. Not for re-intubation.	1
Poor prognosis.	4
Poor prognosis and disease process.	1
Poor prognosis plus drawing of a skull and cross bones.	1
Poor prognosis and deteriorating.	1
Poor prognosis poor. Received 11 days of treatment for PCP. No change.	1
Progressive deterioration, despite resuscitation and inotrope support.	1
Progressive deterioration. Not doing well.	1
RVD and severe pneumonia.	1
Rapid deterioration.	2
Severe symptomatic HIV infection.	1
Slow deterioration.	1
Steady slow deterioration despite intensive treatment.	1
Terminally ill.	6
Terminal illness.	1
Terminal. Draining effusion may precipitate another bleed. Palliation.	1
Terminal. Mechanical ventilation would be futile and is contra-indicated.	1
Terminally ill. Floridly ill.	1

Appendix 3
Verbatim Evidence of Dying (N=83)

Verbatim Evidence	No.
Condition deteriorating, not doing well, not for active resuscitation.	1
Counsel parents on grave prognosis.	1
Counselled parents that patient may die.	1
Counselled Mom regarding poor condition. Probably dying.	1
Counselled parents he may die but we will try our best.	1
Critically ill infant with guarded prognosis.	1
Dying. Not for further intervention at this stage.	1
End stage.	3
End stage and desperately ill.	1
End stage – keep comfortable. Doing badly.	1
End stage AIDS.	3
End stage AIDS and wasting pneumonia (past admission: category C).	1
End stage AIDS (cardiomyopathy).	1
End stage HIV disease. Admitted for terminal care.	1
End stage disease, wasted, terminally ill.	1
End stage from a previous admission.	1
End stage. Preterminal.	1
Extremely poor prognosis.	1
In extremis. No procedures to be done.	1
In extremis. Seems terminal.	1
Moribund.	2
No improvement with aggressive treatment. He is probably dying.	1
Patient dying.	1
Poor outcome.	1
Poor prognosis.	12
Poor prognosis – brain death.	1
Poor prognosis, condition deteriorating.	2
Poor prognosis – terminally ill.	1
Very poor prognosis.	2
Very poor prognosis – not for IV antibiotics.	1
Poor prognosis. Severe pneumonia not responding to treatment.	1
Poor prognosis. Disease severity noted at previous ICU admission.	1
Poor prognosis. Wasting away slowly.	1
Preterminal. End stage AIDS.	1
Preterminal this morning. Looks awful.	1
Probably dying from severe sepsis.	1
Prognosis is bad.	1
Prognosis is poor.	1
Rapidly deteriorating RVD.	1
Rapidly worsening, probably terminal.	1
Severely ill and on maximal treatment. Still no improvement.	1
Strong possibility of demise.	1
Terminal.	8
Terminal HIV disease. Prognosis hopeless.	1
Terminal HIV. End stage.	1
Terminal illness.	3
Terminal lung disease.	1
Terminal phase of AIDS.	1
Terminal pneumonia.	1
Terminal progressive pneumonia.	1
Terminal. No improvement. Continued care futile.	1
Terminally ill – full blown AIDS.	1
Terminally ill.	3
Terminally ill with extensive pneumonia.	1

Appendix 4
Verbatim Comfort Care Plans (N=73)

Comfort Care Plan	No.
Analgesia.	1
Conservative management. If distressed give morphine.	1
Full supportive care.	1
Full supportive care. Keep NPO_2, IV fluids, antibiotics.	1
Keep comfortable. All supportive care on ward.	1
Keep comfortable. Conservative management only.	1
Keep comfortable. Conservative management. HBO_2. Side cubicle.	1
Keep comfortable. Dolorol stat, morphine infusion.	1
Keep comfortable. HBO_2, Panado.	1
Keep comfortable. Morphine PRN, continue treament.	1
Keep comfortable. Morphine if in pain. Cut back fluids.	1
Keep comfortable. Morphine.	1
Keep comfortable. No invasive procedures.	2
Keep comfortable. No IV antibiotics, no X-rays.	1
Keep comfortable. Not for IPPV. Morphine PRN.	1
Keep comfortable. Not for more treatment. Give morphine.	1
Keep comfortable. Terminal care. Soft diet. Fluids.	1
Keep comfortable with morphine and valium. Withdraw curative treatment on grounds of futility.	1
No painful procedures. If restless give morphine po 1mg QID.	1
Not for aggressive investigation. For oral antibiotics and oral morphine.	1
Palliation only.	1
Palliation. Decrease oxygen. Opiates.	1
Palliation. Symptomatic relief. Suggest morphine infusion.	1
Palliation. TLC+++. Stop blood investigations.	1
Palliative care.	1
Palliative care. Dolorol forte, IV antibiotics, NPO_2 , HBO_2.	1
Palliative care. Extubation. Morphine, midazolam to prevent agonal gasping.	1
Supportive care. Chloral hydrate stat. Move to a side cubicle.	1
Supportive care only.	2
Supportive care only. Continue morphine.	1
Supportive care only. Minimum blood taking. Not for IV Bactrim.	1
Supportive care only. Not for further bloods.	1
Supportive care only. Only give platelets if active bleeding.	1
Supportive care only. No repeat tests. Antibiotics for 7 days, then stop.	1
Supportive care. Change goals. Withdraw curative care. Morphine infusion.	1
Supportive care. No more IVs. N-G tube rehydration only.	1
Supportive therapy only. Palliative care only.	1
Supportive treatment. If drip tissues, do not resite.	1
TLC.	7
TLC only.	4
TLC only. Analgesia.	1
TLC only. Do nothing that will cause discomfort.	1
TLC. Continue N-G feeds and antibiotics. Add morphine.	1
TLC. Oral Bactrim (PCP pneumonia).	1
TLC. Analgesia.	1
TLC. Continue oxygen.	1
TLC. Continue feeds. Analgesia PRN if needed.	1
TLC. For conservative management only. No blood products. HBO_2.	1
TLC. Full TPN, adrenaline nebs, morphine as needed.	1
TLC. Keep comfortable. Move to side cubicle.	1
TLC. Keep comfortable. Continue Dolorol. Morphine if needed.	1
TLC. Low dose morphine. Minimal handling.	1
TLC. Moved to side cubicle. Stop curative care.	1
TLC. No procedures. Increase morphine.	1
TLC. Nothing more can be done for the baby.	1
TLC. Palliative care.	1
TLC. Sedation if restless. No invasive investigations.	1
TLC. Treat cardiac failure and maintain comfort with oxygen and morphine.	1
TLC. Try to keep comfortable.	1
Terminal care. Morphine, oral feeds, IV fluids, oral Bactrim.	1
Terminal care. Not for active management. Morphine if needed.	1
Withdraw curative care. Increase morphine, add valium.	1

Appendix 5
Interventions in Last 24 Hours of Life According to Presence of a Do Not Resuscitate Order

End Interventions N = 165			Do Not Resuscitate Order Yes (N = 138)	No (N = 27)		
	N	%	N	N	χ^2	P- value
IV Fluids	133	81%	111	22	0.02	0.9001
IV antibiotics	122	75%	103	19	0.21	0.6451
N-G feeds	**99**	**60%**	**92**	**7**	**15.52**	**0.0000**
Nystatin	88	53%	78	10	3.42	0.0642
HBO_2	**68**	**41%**	**63**	**5**	**6.82**	**0.0090**
Morphine	63	38%	56	7	2.04	0.1530
Panado	**51**	**31%**	**47**	**4**	**3.89**	**0.0485**
Oral antibiotics	44	27%	38	6	0.32	0.5691
NPO_2	45	27%	38	7	0.03	0.8639
Venipuncture	40	24%	30	10	2.86	0.0908
Steroids	35	21%	29	6	0.02	0.8886
Nebulisation	31	19%	27	4	0.33	0.5645
Ventilation	**29**	**18%**	**18**	**11**	**11.89**	**0.0005**
Sedation	28	17%	23	5	0.05	0.8151
X-rays	**27**	**16%**	**18**	**9**	**6.75**	**0.0093**
CPR	**24**	**15%**	**12**	**12**	**23.08**	**0.0000**
Ringers Lactate	**24**	**14%**	**16**	**8**	**5.87**	**0.0153**
Inotropes	**21**	**13%**	**10**	**11**	**22.67**	**0.0000**
Oral feeds	20	12%	18	2	0.67	0.4132
N-G tube	19	11%	13	6	3.61	0.0574
Anticonvulsants	16	10%	13	3	0.07	0.7866
Transfusion	15	9%	10	5	3.45	0.0632
Physiotherapy	14	8%	10	4	1.66	0.1981
Extubation	12	7%	9	3	0.70	0.4024
A line	8	5%	8	0	1.64	0.2313
CVP	8	5%	6	2	1.98	0.2174
Intubation	**7**	**4%**	**3**	**4**	**8.83**	**0.0029**
Muscle relaxants	7	4%	6	1	1.75	0.3202
TPN	2	1%	2	0		
LP	1	1%	1	0		
CT Scan	1	1%	0	0		

Appendix 6
Interventions in Last 24 Hours According to Evidence of Dying

End Interventions N=165			Evidence Yes N=83	Evidence No N=82		
	N	%	N	N	$\chi 2$	P-value
IV fluids	133	81%	66	67	0.13	0.7229
IV antibiotics	122	75%	58	64	1.42	0.2334
N-G feeds	99	60%	51	48	0.14	0.8239
Nystatin	88	53%	44	44	0.01	0.9338
HBO_2	68	41%	34	34	0.00	0.9481
Morphine	**63**	**38%**	**44**	**19**	**15.47**	**0.0000**
Panado	51	31%	26	25	0.01	0.9076
Oral antibiotics	44	27%	23	21	0.09	0.7609
NPO_2	45	27%	24	21	0.23	0.6345
Venipuncture	40	24%	16	24	2.23	0.1354
Steroids	35	21%	21	14	1.66	0.1974
Nebulisation	31	19%	18	13	0.91	0.3389
Ventilation	29	18%	14	15	0.06	0.9713
Sedation	28	17%	17	11	1.45	0.2279
X-rays	27	16%	11	16	1.17	0.2786
CPR	**24**	**15%**	**5**	**19**	**9.70**	**0.0018**
Ringers Lactate	**24**	**14%**	**7**	**17**	**4.99**	**0.0255**
Inotropes	**21**	**13%**	**6**	**15**	**4.52**	**0.0335**
Oral feeds	20	12%	13	7	1.97	0.2445
N-G tube	19	11%	11	8	0.49	0.4830
Anticonvulsants	16	10%	11	5	2.40	0.1215
Transfusion	15	9%	4	11	3.67	0.0555
Physiotherapy	14	8%	9	5	1.19	0.2754
Extubation	**12**	**7%**	**10**	**2**	**5.61**	**0.0178**
A line	8	5%	6	2	2.04	0.1424
CVP	8	5%	6	2	3.64	0.0604
Intubation	7	4%	1	6	3.77	0.0565
Muscle relaxants	7	4%	4	3	0.14	0.7123
TPN	2	1%	1	1	0.00	0.7484
Lumbar Puncture	1	1%	1	0	0.99	0.5030
CT scan	1	1%	1	0	0.99	0.5030

Appendix 7
Interventions in Last 24 Hours According to Presence of a Comfort Care Plan

End Interventions N=165			Comfort Care Plan Yes N=73	No N=92		
	N	%	N	N	$\chi 2$	P-value
IV fluids	**133**	**81%**	**53**	**80**	**5.33**	**0.0209**
IV antibiotics	**122**	**75%**	**45**	**77**	**10.21**	**0.0013**
N-G feeds	99	60%	48	51	1.79	0.1803
Nystatin	88	53%	41	47	0.42	0.5174
HBO_2	68	41%	29	39	0.12	0.7305
Morphine	**63**	**38%**	**34**	**29**	**3.88**	**0.0487**
Panado	51	31%	20	31	0.75	0.3859
Oral antibiotics	44	27%	24	20	2.57	0.1091
NPO_2	45	27%	19	26	0.10	0.7497
Venipuncture	**40**	**24%**	**11**	**29**	**5.96**	**0.0146**
Steroids	**35**	**21%**	**9**	**26**	**6.14**	**0.0131**
Nebulisation	31	19%	14	17	0.01	0.9092
Ventilation	**29**	**18%**	**7**	**22**	**5.73**	**0.0166**
Sedation	28	17%	10	18	0.99	0.3201
X-rays	27	16%	9	18	1.55	0.2134
CPR	**24**	**15%**	**3**	**21**	**11.40**	**0.0007**
Ringers lactate	24	14%	8	16	1.35	0.2458
Inotropes	**21**	**13%**	**5**	**16**	**4.05**	**0.0442**
Oral feeds	20	12%	12	8	2.28	0.1313
N-G tube	19	11%	5	14	2.78	0.0954
Anticonvulsants	16	10%	10	6	2.38	0.1229
Transfusion	**15**	**9%**	**3**	**12**	**3.91**	**0.0480**
Physiotherapy	14	8%	3	11	3.21	0.0732
Extubation	12	7%	5	7	0.03	0.8524
A line	8	5%	3	5	0.15	0.6947
CVP	8	5%	3	5	0.01	0.9400
Intubation	7	4%	2	5	0.72	0.3950
Muscle relaxants	7	4%	1	6	2.64	0.1039
TPN	2	1%	1	1		
LP	1	1%	0	1		
CT Scan	1	1%	0	1		

Appendix 8
Interventions in Last 24 Hours of Life According to Absence of an End of Life Decision

All Interventions N = 165			No Decisions N = 20			
	N	%	N	%	$\chi 2$	P-value[a]
IV fluids	133	81%	17	85%	0.28	0.4282
IV antibiotics	122	75%	16	80%	0.43	0.5114
N-G feeds	99	60%	**4**	**20%**	**15.51**	**0.0000**
Nystatin	88	53%	10	50%	0.10	0.7506
HBO_2	68	41%	**3**	**15%**	**6.42**	**0.0113**
Morphine	63	38%	**3**	**15%**	**5.15**	**0.0232**
Panado	51	31%	4	20%	1.26	0.2615
Oral antibiotics	44	27%	4	20%	0.51	0.4733
NPO_2	45	27%	7	35%	0.68	0.4092
Venipuncture	40	24%	8	40%	3.06	0.0803
Steroids	35	21%	3	15%	0.52	0.3465
Nebulisation	31	19%	2	10%	1.28	0.2076
Ventilation	29	18%	**8**	**40%**	**7.85**	**0.0050**
Sedation	28	17%	3	15%	0.06	0.8029
X-rays	27	16%	**7**	**35%**	**5.74**	**0.0165**
CPR	24	14%	**10**	**50%**	**22.88**	**0.0000**
Ringers Lactate	24	14%	**7**	**35%**	**7.61**	**0.0057**
Inotropes	21	13%	**9**	**45%**	**21.21**	**0.0000**
Oral feeds	20	12%	1	5%	1.08	0.2993
N-G tube	19	11%	**6**	**30%**	**7.59**	**0.0058**
Anticonvulsants	16	10%	1	5%	0.57	0.4502
Transfusion	15	9%	4	20%	3.26	0.0711
Physiotherapy	14	8%	3	15%	1.24	0.2661
Extubation	12	7%	1	5%	0.17	0.6772
A line	8	5%	0	0%	1.15	0.3471
CVP	8	5%	0	0%	1.00	0.3975
Intubation	7	4%	**3**	**15%**	**0.44**	**0.0111**
Muscle relaxants	7	4%	1	5%	0.03	0.6024
TPN	2	1%	0	0%		
Lumbar Puncture	1	1%	0	0%		
CT Scan	1	1%	0	0%		

[a] Significantly different from patients *with* an end of life decision.

Appendix 9
Verbatim Documentation of Pain and Distress in Last 48 Hours of Life in Patients WITH a Comfort Care Plan: Case Summaries (N=38)[a]

Record	Case Summary
22*[b c]	**4 months; Category C; 30 days** **Symptomatology**: Recessing+++. Recessing+++. (Repeated entries) **Evidence of Dying**: Terminal, progressive pneumonia **CCP**: TLC. Do nothing that will cause discomfort. **End Interventions**: N-G feeds, Nebs, HBO_2, Nystatin, Steroids **Analgesia**: None (Registrar recommended morphine if necessary in clinical notes, never written in medicine chart.)
26**	**9 months; Category C; 2 days** **Symptomatology**: Penile ulceration **Evidence of dying**: End stage AIDS **CCP**: Terminal care – morphine, oral feeds, IV fluids, oral Bactrim **End Interventions**: NPO_2 , Bloods, IV antibiotics, Nystatin, Gastric washings, Flumazine dressings, Morphine **Analgesia**: Morphine 4 hourly (3 doses)
32*	**20 months; Category C; 51 days** **Symptomatology**: Distressed+++. Still distressed+++. In HBO_2 but remains distressed. **Evidence of dying**: Poor prognosis **CCP**: Keep comfortable. Not for more treatment. Give morphine. **End Interventions**: N-G feeds, HBO_2, IV fluids, Oral antibiotics, Orobase, Panado, Morphine **Analgesia**: Panado 6 hourly, Morphine (10/12 doses - commenced 5 days after it was prescribed in CCP.)
34***	**6 months; Category C; 36 days** **Symptomatology**: Respiratory distress. Recessing+++. Skin on patient's back excoriated. Recessing+++. Still recessing+++. Distressed on NPO_2. Very much distressed (sic) **Evidence of dying**: Poor prognosis **CCP**: Terminal care – not for active management. Morphine if distressed. Move to side cubicle. **End Interventions**: Oral feeds, N-G feeds, Nebs, HBO_2, Oral antibiotics, Nystatin, Panado, Morphine **Analgesia**: Morphine (1 dose)
35***	**3 months; Category B; 35 days** **Symptomatology**: Distressed+++. Recessing. Hyperinflated. Recession+++. Gasping – held oxygen to mouth to inhale but still gasping. Doctor said to "Keep comfortable". **Evidence of dying**: None **CCP**: Keep comfortable. Conservative management only. **End Interventions**: Nebs, HBO_2, IV fluids, IV antibiotics, Nystatin **Analgesia**: None
38*	**4 months, Category B; 7 days** **Symptomatology**: Recessing+++. Recessing+++. (Several entries) **Evidence of dying**: Poor prognosis. Condition deteriorating. **CCP**: Keep comfortable. Give all supportive ward care. **End Interventions**: Oral feeds, Nebs, NPO_2, HBO_2, IV fluids, IV antibiotics, Nystatin, Steroids **Analgesia**: None
39**	**5 months; Category C; 30 days** **Symptomatology**: Riddled with extensive oral candida **Evidence of dying**: End Stage. Doing badly. Keep comfortable. **CCP**: TLC. No procedures. Increase morphine. **End Interventions**: Oral feeds, garlic, Betadine, Morphine **Analgesia**: Morphine 6 hourly (6 doses)
41*	**12 months; Category C; 25 days** **Symptomatology**: Buttocks very sore. Child even more distressed this morning. **Evidence of dying**: In extremis **CCP**: TLC. No procedures. Increase morphine. **End Interventions**: N-G feeds, Nebs, HBO_2, IV fluids, IV antibiotics, Nystatin, Morphine **Analgesia**: Morphine 4 hourly (9 doses)
44*	**3 months; Category B; 8 days** **Symptomatology**: Recessing++. On HBO_2 but remains distressed++. **Evidence of dying**: Terminal pneumonia, deteriorating in spite of best medical care. **CCP**: Palliation. Suggest morphine infusion to relieve respiratory symptoms (PICU consultant's opinion) **End Interventions**: N-G feeds, HBO_2, IV fluids, IV antibiotics, Nystatin, Morphine **Analgesia**: Morphine (1 bolus infusion less than 1 hour before death)

Table continued.

46* **31 months; Category C; 17 days**
Symptomatology: Flaring and recessing+++. Visibly distressed. Herpes getting worse. Laboured breathing. Very distressed at night. Still very distressed but on oxygen and nebs.
Evidence of dying: None
CCP: Continue palliative care: dolorol forte, IV antibiotics, NPO_2, HBO_2
End Interventions: Nebs, NPO_2, Oral antibiotics, IV antibiotics, Nystatin, Panado, Dolorol forte
Analgesia: Panado 4 hourly (31/50 doses), Dolorol forte (24/33 doses)

48* **27 months; Category C; 7 days**
Symptomatology: Very distressed. Patient restrained because she is pulling oxygen tube out of her nose.
Evidence of dying: Terminally ill. Full blown AIDS.
CCP: Supportive therapy only. Palliative therapy only.
End Interventions: Oral feeds, NPO_2, Oral antibiotics, Nystatin, Morphine
Analgesia: Morphine 4 hourly (6 doses)

50 **3 months; Category C; 5 days**
Symptomatology: Severe oral thrush
Evidence of dying: None
CCP: TLC. Low dose morphine. Minimal handling.
End Interventions: Nebs, HBO_2, Nystatin, IV fluids, Steroids, Morphine, Garlic, CPR (despite DNR order)
Analgesia: Continuous IV infusion of morphine (following recommendation of PICU consultant post-CPR)

54 **6 months, Category C, 3 days**
Symptomatology: Oral thrush+++. Skin lesion pustules
Evidence of dying: None
CCP: No painful procedures. If restless, give morphine po 1mg QID.
End Interventions: N-G feeds, Oral antibiotics, IV antibiotics, Nystatin, Betadine, Morphine
Analgesia: Morphine 6 hourly (3 doses)

58* **6 months, Category C; 35 days**
Symptomatology: Extensive oral candida. Weak cry even though in great pain.
Evidence of dying: None
CCP: Not for aggressive investigation. For oral antibiotics and oral morphine
End Interventions: N-G feeds, Oral antibiotics, Nystatin, Panado, Morphine
Analgesia: Panado PRN, Morphine 4 hourly (9 doses)

69* **5 months; Category C; 28 days**
Symptomatology: Buttocks still excoriated
Evidence of dying: Terminal HIV. End stage
CCP: TLC
End Interventions: N-G feeds, IV fluids, IV antibiotics, Morphine
Analgesia: Morphine (1 dose a few hours before death)

76* **60 months, Category C; 44 days**
Symptomatology: Self report of pain in the stomach
Patient complains of abdominal pain. (Several self reports during admission, including day of death)
Evidence of dying: None
CCP: TLC. Keep comfortable. Continue Dolorol and morphine if necessary.
End Interventions: Oral feeds, Oral antibiotics, Panado, Morphine, TB medicines
Analgesia: Panado, Morphine (6 doses)

85 **110 months; Category C; 16 days**
Symptomatology: Patient complaining of chest pain. (Doctor's plan: "Something for pain")
Evidence of dying: End stage
CCP: Keep comfortable. No invasive procedures.
End Interventions: NPO_2, Physiotherapy, IV fluids, Oral antibiotics, Garlic
Analgesia: None

89* **3 months; Category C; 26 days**
Symptomatology: Recessing+++ and distressed
Evidence of dying: Poor prognosis
CCP: TLC. Nothing more can be done for the baby.
End Interventions: Nebs, HBO_2, IV fluids, IV antibiotics, Steroids, Morphine
Analgesia: Morphine (I oral dose 15 minutes before death)

92 **12 months; Category B; 2 days**
Symptomatology: Extensive and severe dermatitis. Otitis++.
Evidence of dying: None
CCP: TLC. Palliative care.
End Interventions: N-G feeds, Bloods, IV fluids, Ringers, Oral antibiotics, Nystatin
Analgesia: None

Table continued.

95* **7 months; Category C; 3 days**
Symptomatology: Coughing up blood continuously.
Evidence of dying: End stage and desperately ill.
CCP: Supportive care only. Minimum blood taking. Not for IV antibiotics.
End Interventions: N-G feeds, Nebs, HBO_2, Xrays, IV fluids, IV antibiotics, Ringers, Sedation
Analgesia: None. (1 dose of chloral hydrate 1 hour before death. Morphine prescribed, never administered.)

98** **2 months; Category B; 4 days**
Symptomatology: Oral and oesophageal thrush+++. Pseudomonas skin sepsis.
Evidence of dying: Probably dying from severe sepsis.
CCP: TLC. Continue oxygen.
End Interventions: N-G feeds, Nebs, HBO_2, IV fluids, Nystatin, Sedation
Analgesia: None (1 dose of chloral hydrate 45 minutes before death)

110* **11 months; Category C; 13 days**
Symptomatology: Extremely exhausted. Recessing+++. Buttocks still very sore. Both feet and hands swollen. (Dr called a few hours before death: Seen by Dr G "...commence on ½ DD IVI infusion at 24 dpm. Continue adrenaline nebs.")
Evidence of dying: Poor prognosis
CCP: Palliation, TLC+++. Stop blood investigations.
End Interventions: N-G feeds, Nebs, Bloods, IV fluids, Oral antibiotics, Nystatin, TB medicines
Analgesia: None

116* **12 months; Category C; 2 days**
Symptomatology: Abdo distended+++
Evidence of dying: Strong possibility of demise
CCP: Keep comfortable, Dolorol stat, morphine infusion
End Interventions: N-G drainage tube, HBO_2, IV antibiotics, Anticonvulsants, Dolorol, Morphine
Analgesia: Dolorol forte (1 bolus), Morphine (1 oral dose)

119*** **2 months, Category C; 9 days**
Symptomatology: Marked recession. Still very distressed. Extensive skin rash. Distressed+++. Still distressed+++. Recessing+++.
Evidence of dying: None
CCP: Full supportive care. For IV antibiotics, continue IV Ampicillin and Gentamycin, Nystatin and HBO_2
End Interventions: N-G feeds, HBO_2, IV antibiotics, Nystatin
Analgesia: None

121* **4 months; Category C; 16 days**
Symptomatology: Recessing++++. Tried to keep baby comfortable. Shallow rapid respiration (last 12 hours)
Evidence of dying: Poor prognosis. Not for IV antibiotics.
CCP: TLC only, continue N-G feeds, antibiotics, add morphine.
End Interventions: N-G feeds, HBO_2, Oral antibiotics, Nystatin, Morphine, Lasix
Analgesia: Morphine 6 hourly (15 doses)

130* **4 months; Category C; 31 days**
Buttocks red and bleeding. Miserable child.
Evidence of dying: Poor prognosis
CCP: Supportive care. No more IV therapies. N-G tube rehydration only.
End Interventions: N-G feeds, Nystatin,
Analgesia: None

134* **8 months; Category C; 5 days**
Symptomatology: Buttocks excoriated and very sore. Mouth red and sore. Facial oedema worse. Seen by consultant: "Continue palliative care."
Evidence of dying: Preterminal. Looks awful. Stat morphine.
CCP: Palliation only
End Interventions: N-G feeds, IV fluids, IV antibiotics, Nystatin
Analgesia: None (Morphine written in medical chart, never administered.)

137* **7 months; Category B; 6 days**
Symptomatology: Buttocks excoriated. Mouth and buttocks very sore.
Evidence of dying: Condition deteriorating, not doing well.
CCP: Supportive care only. No repeat tests. No blood products. HBO_2
End Interventions: N-G feeds, NPO_2, IV fluids, IV antibiotics, Nystatin
Analgesia: None

141* **3 months; Category C; 39 days**
Symptomatology: Distressed and recessing+++. Awake most of the night.
Evidence of dying: None
CCP: TLC. Oral Bactrim
End Interventions: N-G feeds, HBO_2, Oral antibiotics, Steroids, Morphine, Joules Solution
Analgesia: Morphine 8 hourly (2 doses)

Table continued.

142* **14 months; Category B; 2 days**
Symptomatology: Irritability+++
Looks anxious, hardly slept till time of report (02h15).
Evidence of dying: Terminal
CCP: Keep comfortable. Morphine PRN
End Interventions: HBO_2, Bloods, Xrays, Transfusion, Inotropes, IV fluids, Panado, ECHO
Analgesia: Panado 6 hourly. (Morphine recommended in CCP, never written on medicine chart.)

145* **9 months; Category C; 79 days**
Symptomatology: Distressed, battling to breathe. Jittery.
Evidence of dying: Prognosis is bad. (14 days after admission, student intern requested physiotherapy to prevent contractures. Registrar "...leave physio because prognosis is so bad". Next identified as dying on day 78: End stage)
CCP: Supportive care only. Only give platelets if active bleeding (day 61)
End Interventions: N-G feeds, IV fluids, Oral antibiotics, Cisapride
Analgesia: None

147* **6 months; Category C; 3 days**
Symptomatology: Penis excoriated. Skin lesions on face, legs and elbows.
Registrar and consultant tried all afternoon to resite drip (12 hours before death).
Evidence of dying: End stage. Preterminal.
CCP: Keep comfortable. Conservative management. Move to side cubicle. HBO_2
End Interventions: HBO_2, Bloods, IV fluids, Oral antibiotics, Nystatin, Morphine
Analgesia: Morphine (1 oral dose)

148* **10 months; Category B; 5 days**
Symptomatology: Abdo distended+++. Seems in pain. Black necrotic stoma.
Evidence of dying: None
CCP: Analgesia
End Interventions: IV fluids, Stoma care, Morphine
Analgesia: IV morphine. Infusion increased in last few hours.

149* **1 month; Category B; 13 days**
Symptomatology: Skin peeling, nappy rash with deep sores. Buttocks very sore.
Evidence of dying: None
CCP: Full supportive care. Keep NPO_2, IV fluids, antibiotics.
End Interventions: N-G feeds, IV fluids, IV antibiotics, Nystatin, Acyclovir, CPR (despite DNR order)
Analgesia: None

151* **4 months; Category B; 14 days**
Symptomatology: Severe stomatitis, extensive skin lesions, sepsis.
Skin excoriated. Still looks horrible. Bleeding from the mouth.
Evidence of dying: Dying, not for further interventions at this stage.
CCP: TLC. Try to keep comfortable.
End Interventions: Oral feeds, HBO_2, Oral antibiotics, IV antibiotics, Nystatin
Analgesia: None (Panado written on medicine chart, never administered.)

154** **11 months; Category C, 7 days**
Symptomatology: Candida and nappy rash+++
Evidence of dying; None
CCP: Keep comfortable. Morphine if in pain. Cut back fluids.
End Interventions: N-G feeds, NPO_2, IV fluids, IV antibiotics, Nystatin, Anticonvulsants
Analgesia: None. (Morphine never written on medicine chart despite CCP)

158* **3 months; Category C; 9 days**
Symptomatology: Buttocks excoriated. Oral thrush+++
Mouth very sore. Mouth very sore+++. (Repeated entries)
Evidence of dying: Terminally ill
CCP: TLC only
End Interventions: NPO_2, IV fluids, IV antibiotics, Morphine
Analgesia: Morphine 6 hourly (5 doses)

161* **2 months; Category B; 6 days**
Symptomatology: Looks distressed, gasping. High oxygen requirements. Still distressed+++.
Evidence of dying: Poor prognosis
CCP: Keep comfortable. Morphine if necessary. Move to side cubicle.
(Last entry: "Found not breathing and a vomit on linen saver. R.I.P.")
End Interventions: N-G feeds, HBO_2, Physiotherapy, IV fluids, IV antibiotics, Nystatin, Steroids, TB medicines
Analgesia: Morphine (1 dose a few hours before death

---

[a] Excludes patients who died in the PICU.
[b] *Nursing notes only **Medical notes only ***Medical and nursing notes
[c] Highlighted records indicate administration of analgesia (Panado, Dolorol and Morphine)

Appendix 10
Verbatim Documentation of Pain and Distress in Last 48 Hours of Life in Patients WITHOUT a Comfort Care Plan (N=34)

Record[a]	Pain and Distress
1*[b]	Oral thrush+++. Abdomen distended+++.
8*	Chronic supporative otitis.
11**	Distended+++. Breathing with difficulty.
17***	Working hard...needs IPPV. Terrible coughing spells. Very restless.
18**	Abdomen distended+++.
19***	Still uses a lot of effort for breathing. Still recessing+++. Very distressed. Nebs of little effect. Still distressed+++. (18x nebs on the hour on last day)
24*	Extensive oral ulceration.
33*	Very sore mouth. Very sore mouth. Mouth is very sore. (Repeated entries over period)
36*	Recessing+++.
40*	Bad coughing spells. Drip resited day of death.
43***	Oral candida+++ Recessing+++. Troublesome cough. Cyanosed.
59*	Severe oral thrush. Mouth very sore.
63*	Mouth very sore. Abdomen distended+++.
66*	Recessing, gasping. Patient very uncomfortable. Abdomen distended+++.
67*	Recessing+++. Short of breath. HBO_2 given. Still short of breath.
73***	Laboured, acidotic breathing. Working hard. Not looking good. Acidotic breathing. Lethargic.
74*	Oral thrush+++.
82***	Severe nappy rash. Mouth sore. Disseminated herpes. Buttocks and vaginal area too sore for urine bag to stick.
91**	Severe thrush. Distended abdomen+++ (NEC).
93**	Oral and oesophageal thrush+++.
99***	Working very hard. Recessing+++. Patient remains lethargic and distressed.
101***	Distressed+++. Recessing+++. Oral thrush+++.
103***	Distension+++. Abdomen distended+++. Very distressed.
106*	Very distressed with nasal flares, gasping respiration. Still very distressed. (Repeated entries).
107*	Patient complained of pain in the ribs.
108*	Oral thrush+++. Distressed+++.
114*	Very restless. Recessing++.
120***	Extensive oral thrush. Stop nebs – increasing distress. Cyanotic. Cold. Kusmall breathing Very distressed. Vomiting and coughing.
123**	Distressed+++. Eyes wide open, looks very anxious. Hardly slept. (Entry by student intern)
135*	Buttocks excoriated+++. Buttocks very sore. (Repeated entries)
144*	Very miserable. Cries when handled. Very distressed.
150***	Skin lesions++++ and ulceration. Distended+++.
156***	Abscess and distinct lesions – painful to touch. Staph osteitis. Hot, red swollen arm – very tender to touch.
164***	Oral candidiasis and ulceration. Mouth still very sore. Dry bloody crust on both lips. Buttocks still very sore. Respiratory distress+++.

[a] Highlighted records indicate administration of analgesia (Panado x8, Morphine x7).

[b] *Nursing notes only **Medical notes only ***Medical and nursing notes

Appendix 11
Patients in Pain and Distress in Last 48 Hours of Life WITH a Comfort Care Plan Life: Summary Distribution of Demographic and Clinical Characteristics and End of Life Decisions (N=38)[a]

Patient record	Age (m)	Severity	Length of stay (d)	DNR	Evidence of dying	Analgesia (mild/ moderate)	Morphine	Sedation
22*[b]	4	C	30	Y	Y	N	N	N
26**	9	C	2	Y	Y	N	Y	N
32*	20	C	51	Y	Y	Panado	Y	N
34***	6	C	36	Y	Y	N	Y	N
35***	3	B	7	Y	N	N	N	N
38*	4	B	7	Y	Y	N	N	N
39**	5	C	30	Y	Y	N	Y	N
41*	12	C	25	Y	Y	N	Y	N
44*	3	B	8	Y	Y	N	Y	N
46***	31	C	17	Y	N	Panado & Dolorol	N	N
48*	27	C	7	Y	Y	N	Y	N
50**	3	C	5	Y	N	N	Y	N
54**	6	C	3	Y	N	N	Y	N
58*	6	C	35	Y	N	Panado	Y	N
69*	5	C	28	Y	Y	N	Y	N
76***	60	C	44	Y	N	Panado	Y	N
85**	110	C	16	Y	Y	N	N	N
89*	3	C	26	Y	Y	N	Y	N
92**	12	B	2	Y	N	N	N	N
95*	7	C	3	Y	Y	N	N	Chloral Hydrate
98**	2	B	4	Y	Y	N	N	Chloral Hydrate
110*	11	C	13	Y	Y	N	N	N
116*	12	C	2	Y	Y	Dolorol Forte	Y	N
119***	2	C	9	Y	N	N	N	N
121*	4	C	16	Y	Y	N	Y	N
130*	4	C	31	Y	Y	N	N	N
134*	8	C	5	Y	Y	N	N	N
137*	7	B	6	Y	Y	N	N	N
141*	3	C	39	Y	N	N	Y	N
142***	14	B	2	Y	Y	Panado	N	N
145*	9	C	79	Y	Y	N	N	N
147***	6	C	3	Y	Y	N	Y	N
148*	10	B	5	Y	N	N	Y	N
149*	1	B	13	Y	N	N	N	N
151***	4	B	14	Y	Y	N	N	N
154**	11	C	7	Y	N	N	N	N
158***	3	C	9	Y	Y	N	Y	N
161*	2	B	6	Y	Y	N	Y	N

[a] Excludes patients who died in the PICU

[b] *Nursing notes only ** Medical notes only ***Medical and nursing notes

Appendix 12
Patients in Pain and Distress in Last 48 Hours of Life WITHOUT a Comfort Care Plan: Summary Distribution of Demographic and Clinical Characteristics and End of Life Decisions (N=34)[a]

Patient record	Age (m)	Severity	Length of stay (d)	DNR	Evidence of dying	Analgesia (mild)	Morphine	Sedation
1*[b]	3	C	3	N	N	N	N	N
8*	3	C	5	N	Y	N	N	N
11**	7	C	26	Y	Y	N	Y	N
17***	2	B	2	Y	Y	N	N	N
18**	2	B	1	Y	N	N	N	N
19***	4	C	5	Y	Y	N	N	Chloral Hydrate
24*	17	C	25	N	N	Panado	N	N
33*	6	B	30	Y	Y	N	N	N
36*	4	B	6	Y	N	N	Y	N
40*	3	B	12	Y	Y	N	N	N
43***	4	B	5	Y	N	N	Y	N
59*	3	B	2	Y	N	N	N	N
63*	3	C	6	N	N	N	N	N
66*	25	C	5	N	N	N	N	N
67*	2	B	5	N	N	N	N	N
73***	37	C	8	Y	N	Panado	N	N
74*	4	C	1	Y	N	Panado	Y	N
82***	9	C	9	Y	N	N	N	N
91**	7	C	6	N	N	N	N	N
93**	4	C	5	Y	N	N	N	N
99***	5	C	11	Y	N	Panado	N	N
101***	2	B	4	Y	N	Panado	N	N
103***	4	B	5	Y	Y	N	N	N
106*	4	C	12	Y	N	N	Y	N
107*	4	B	5	Y	Y	N	N	N
108*	4	C	3	Y	N	Panado	N	N
114*	4	C	6	Y	N	N	N	N
120***	3	C	10	Y	N	N	N	N
123**	3	B	8	Y	N	N	N	N
135*	5	B	16	Y	Y	N	N	N
144*	17	C	88	Y	Y	N	Y	N
150***	1	B	2	Y	Y	N	Y	N
156***	5	C	3	Y	N	Panado	N	N
164***	17	C	5	Y	N	Panado	N	N

[a] Excludes patients who died in the PICU
[b] *Nursing notes only **Medical notes only ***Medical and nursing notes