An Analysis of Paediatric Palliative Care in the State of Victoria

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ABSTRACT

The concept of palliative care as an holistic approach to the management of patients with incurable conditions has its roots in the hospice movement. It has since grown into an established field of practice for health professionals of all disciplines and has been recognised as a medical specialty since 1987. Palliative care remains relatively underdeveloped in the paediatric setting for a number of reasons. Firstly, death in childhood is now relatively rare due to the advent of antibiotics, immunisation and advances in the treatment of malignancies. This means that any health professional's individual exposure to palliative care issues is limited, making the development and maintenance of skills difficult. Secondly, the traditional model of palliative care, as a path to be taken when all curative options have been explored, does not adequately serve children and adolescents where the transition to palliative care may be less clear due to a broader range of diagnoses and patterns of disease progression. Children also present added dimensions to palliative care including developmental, ethical and physiological considerations. The involvement of parents as care givers and decision makers further increases the complexity of providing palliative care.

Research is lacking and the evidence on which to base practice is limited. Nevertheless, there are theoretical constructs that can be utilised to build a framework for research in this area. The works of Glaser and Strauss, Corr and Copp on theories of death and dying coupled with earlier works by Freud, Erikson and Piaget on theories of childhood development provide a suitable theoretical framework. Corr's 'task' based model described in 1992 allows us to view the process of providing pediatric palliative care from many different perspectives, and thus provides for a rich multi-dimensional model of pediatric palliative care to be constructed.

This study was done to analyse and investigate the knowledge, attitudes and needs of both providers and recipients of palliative care in a major tertiary paediatric hospital, the Royal Children's Hospital (RCH), Melbourne, Australia and, in addition, to examine various models of delivery of paediatric palliative care in use around the world, and to identify from the literature the constituents of care that make up 'best practice' as regards paediatric palliative care. From this investigation it is hoped to develop a model of care that will best serve the RCH and its patients.

Both qualitative and quantitative research methodologies were used to ascertain not only attitudes, but the prevalence of that attitude among the staff of the hospital. Data from interviews with staff and parents were qualitatively analysed for themes that could be grouped together to reveal information about the processes of delivering and receiving palliative care, and the relationships involved in that process. A quantitative analysis of staff responses to a questionnaire, developed from an early thematic analysis of a small number of staff interviews, revealed the prevalence of those attitudes throughout the medical and nursing participants in this study.

The experiences of the staff and patients of the RCH who participated in this project reflect those of other centres around the world as described in the literature. Limited discussion and education on the subjects of death and bereavement negatively influence communication patterns and practices throughout the hospital. Services are not well integrated and links between the hospital and the community sectors are weak. Children with palliative care needs are often identified late, and home care is not offered in all potentially appropriate cases. There is a lack of knowledge of and confidence in community agencies.

The themes that are presented in the findings of this research describe many tasks involved in providing palliative care to children, by a wide range of personnel from health professional groups, and also by family members. These tasks would fit with the task based model earlier described by Corr. There is discussion around ways to remedy deficiencies in care, improve communication between the hospital and community sectors and to provide improved education and resources to those involved in providing palliative care to children.

Declaration

I, David Sutton declare that the Master by Research thesis entitled 'An Analysis of Pediatric Palliative Care in the State of Victoria', is no more than 60,000 words in length, exclusive of tables, figures, appendices, references and footnotes. The thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Name....................................

Date...................................

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I would like to express my sincere appreciation to the following people for their support and encouragement to undertake this research.

Chapter 1 Introduction

1.0 Introduction

This thesis will examine issues around the development of a paediatric palliative care programme in a major tertiary paediatric treatment centre. It will begin by reviewing various models of paediatric palliative care in use around the world. In addition, the organization and delivery of palliative care in Victoria, Australia, will be examined and the differences between adult and paediatric palliative care will be detailed. The research will be undertaken using a mixed method approach, using both qualitative and quantitative techniques in gathering and analysing the data. The rationale behind this choice will also be described and questions regarding the rigour and ethics of the research will be explored.

Findings from staff and parent interviews will form the basis for recommendations about the organization and delivery of palliative care to children at the Royal Children's Hospital, Melbourne, Australia.

This research project was submitted to the ethics committees of both the Royal Children's Hospital and Victoria University, and carries ethics clearance number(s) HR4/98 (HREC 98/15) from Victoria University, and 97047B from the Royal Children's Hospital.

1.1 Background to the study

The care of adults who are dying has changed dramatically in the last 25 years, with the development of hospice and palliative care, and the provision of medical and nursing programmes that provide a better environment and significantly improved care for the dying person. The concept of palliative care as 'the active total care of patients whose disease is not responsive to curative treatment' (World Health Organisation, 1998) applies equally to children with life-threatening illnesses, however there are a number of reasons why the practice of palliative medicine is different in the paediatric setting. Among these differences are the developmental, physiological and ethical issues encountered in the care of children, but of equal relevance are the low numbers of the paediatric patient population and the diagnostic diversity encountered within it.

Although palliative care services in Australia do not apply restrictive criteria in terms of age or diagnosis, fewer than 10% of patients in the care of these services have diagnoses other than malignancy and 80% are aged over 55 years (Palliative Care Australia, 1998). Thus, the experience of palliative care professionals is limited in regard to children and the conditions they suffer, many of which are rare and encountered only in paediatric practice. Exposure of individual paediatric medical and nursing staff to palliative care issues may be also be limited however, as a result of the relative rarity with which death occurs in childhood. As a consequence, paediatric medical, nursing and allied health staff may not feel adequately skilled to deal with dying patients and their families.

Like adults, children die from disease, but unlike mainstream adult nursing and medicine, paediatrics has been slow to include the concepts of palliative and hospice care for dying children in a formal way. Paediatric nursing espouses itself as providing family-centered care, and its apparent ignoring of the very situation in which children would most need the maximum support of their family and friends in a familiar environment, as well as receiving nursing care of the highest standard, is a significant problem.

Corr and Corr (1985a) have described hospice care as a philosophy rather than a facility. In expanding on this, Corr and Corr also describe hospice care as a form of palliative care that maximizes quality of life when a chance of cure is not a reasonable expectation. Later, Corr & Corr (1992) stated that 'Palliative care in hospice mode lies within the historical mainstream of good nursing...it is not an aberration or departure from, much less an antithesis to that tradition' (p. 431).

Although malignancies comprise the largest single diagnostic group in paediatric palliative care, they may account for only a third of children with palliative care needs. Other important diagnostic categories include metabolic disorders, neurological conditions, cystic fibrosis, congenital anomalies and immune deficiencies. Goldman, Neardsmore and Hunt (1990) have identified four groups of patients, each having different patterns of disease progression in the paediatric setting, that require palliative care. They are:

- Conditions for which potentially curative treatment has failed (eg. malignancy), Group 1.
- Conditions where intensive treatment may prolong and enhance life but premature death occurs (eg. cystic fibrosis), Group 11.
- Progressive conditions where treatment is almost exclusively palliative and may extend over many years (eg. neurodegenerative conditions), Group 111.
- Non-progressive neurological conditions which result in an increased susceptibility to complications and premature death (eg. severe cerebral palsy), Group 1V.

Children with malignancies are generally treated palliatively when curative options have been exhausted and in many cases this comes at a readily identifiable point in time, for example, relapse or a failed bone marrow transplant. In circumstances where the disease process is chronic or progressive however, the transition from a curative to a palliative focus of care may be less clear (Frager, 1996). Similarly, the time for which palliative care is required varies enormously and may be from days to years, depending on the underlying condition. The needs of some children with life-limiting conditions are also growing increasingly complex and may include such interventions as home ventilation (Campbell & Pearce, 1998).

1.2 Palliative care at the Royal Children's Hospital

The Royal Children's Hospital (RCH) is a 346 bed tertiary paediatric hospital. The RCH is regarded in Victoria as the principal institution for the care of paediatric patients. It acts as a tertiary and quaternary referral point for other regional providers of paediatric care, and in 2000/01 had 28,714 inpatients and nearly 200,000 occasions of service for outpatients (Womens and Children's Health, 2001). Whilst there are other tertiary paediatric centres in Victoria, these are mainly neonatal nurseries, and a small population of children who are cared for, at a tertiary level or higher, by the Monash Medical Centre.

The RCH was chosen as the site for this research because the author has extensive experience working with children with terminal illness in this setting. It was hoped that this experience would lead to a greater insight into the problems of providing

such care and provide a sound basis for the development of the project, the data collection and subsequent analysis. In addition, the author has strong links with many of the medical, nursing and paramedical staff, which facilitated their involvement in this research.

Although a dedicated palliative care program does not exist, the following services are available for children with palliative care needs and their families:

1.2.1 Inpatient services

According to the Women's and Children's Health, Annual Report, 2001, the following services for inpatients are available at the RCH:

- Medical and nursing care including specialist oncology, neuro-oncology, cardiac, neurology, respiratory, gastroenterology, neonatal and genetic/metabolic services.
- Nursing care managers for those with complicated conditions or chronic illness.
- Allied health support including social work, physiotherapy, occupational therapy and mental health.
- Pain team, comprising anaesthetists and a clinical nurse consultant who provide a consultative service to children with acute and chronic pain.
- Pastoral care with access to representatives of a wide range of denominations.
- Parent accommodation.

1.2.2 Outpatient services

Further examination of the Women's and Children's Health, Annual Report, 2001 also shows that the following services are available for outpatients at the RCH:

- Outpatient medical services provided on site and at certain rural centres throughout Victoria.
- A Home and Community Care Program provides a variety of home-based nursing, allied health and respite services. Approximately 15 patients with life-threatening illnesses die each year while under the care of this program.

- Links with the Royal District Nursing Service and other organizations such as Very Special Kids Inc. (VSK). Some units within the hospital have formed stronger links than others.

Whilst this is an impressive list of services available to patients, in practice these services are often not well integrated and do not communicate with each other in an effective way. Patients and families often experience frustrating delays whilst information is sought from other departments within the hospital. Similarly communication to community agencies that are involved in providing care and support to patients of the RCH seldom occurs in a timely manner (Sach, 1997).

1.2.3 Bereavement counselling

Parents are generally offered an appointment with their paediatrician after their child's death. Most clinicians either forward a letter or phone the family to encourage their attendance. Social workers also facilitate appointments in some cases. Whilst follow-up by consultant clinicians does not systematically occur with families who do not attend, social workers frequently maintain contact with the family after the child's death.

Bereavement support services are coordinated by the Social Work department and comprise a Bereavement Support Group (BSG), a monthly newsletter, sibling groups and an annual memorial service. The department also takes an active role in providing education to welfare and nursing students as well as community agencies.

Theoretically, the coordinators of the BSG receive notification of all hospital deaths from the Department of Anatomical Pathology and / or Medical records. However, in practice, this does not occur in a consistent or timely fashion. Once notified, the coordinators send a copy of the BSG newsletter to bereaved families together with an invitation to attend their monthly groups. Parent support groups are facilitated by one of the coordinators and guest speakers are invited to every second meeting. Limited facilities for individual counselling are available at the parents' request. There is no outreach service but families may be referred to services in the community. Whilst community agencies involved with bereaved families frequently contact the BSG

seeking assistance and expertise, funding issues severely restricts the availability of services.

1.2.4 Services for RCH staff

In addition to these patient services, the following services are available for staff:

- A psychologist is available at short notice for staff experiencing emotional difficulties and provides individual counselling as well as group work in the form of debriefing sessions. This has been a recent development.

- A peer support program aims to provide support to employees through a network of specially trained co-workers who support staff in coping with work and personal related issues within a totally confidential framework. The program also seeks to increase awareness of acute and chronic stressors within the hospital environment.

Both these services are not used by the majority of RCH nursing or medical staff. The psychologist is viewed by staff members as directly accountable to the hospital management, and whilst this may or may not be true, the suspicion of dubious allegiance leads staff members to be guarded in opening up to them on issues that are causing distress (Author's personal communication with staff members). At the same time the 'peer support program' relies heavily on nursing staff taking on a counselling role with their peers, which inevitably leads to an increase in the stress levels of the 'counsellor' staff member as they try to come to grips with their peers' issues. No extra support or training is given to those who undertake the counselling role.

1.2.5 Palliative care policy at the RCH

A policy exists within the hospital entitled *'Withholding or Withdrawing Life Sustaining Treatment'* (RCH Policy and Procedure Manual, 2000). A proforma of the same title exists, but its use is optional and at the discretion of individual consultants. For patients in three of the groups described by Goldman *et al.* (1990) who were undergoing palliative care, the discussion of 'not for resuscitation' orders by the treating team and palliative care agency was of paramount importance in determining their subsequent management. This policy states that (RCH Policy and Procedure Manual, 2003):

> ...it is sound medical practice and in the best interests of patient care, to withhold or withdraw life-sustaining treatment from patients when death is

almost certain regardless of treatment, or if to continue treatment is not in the best interests of the patient (p. 1).

It is also recommended in the policy that:

Consultants…discuss in advance with parents (and patients where age-appropriate), what actions would be in the patient's best interests if acute life-threatening events supervene (p. 2).

Both these statements are congruent with the philosophy behind palliative care of enhancing the quality of life and being a total approach to the care of the patient.

The next chapter will explore the literature findings related to the subject of paediatric palliative care, the differences between adult and paediatric palliative care, patient and family needs and, in addition, statements regarding 'best practice' in this area will be described.

Chapter 2 Literature review

2.0 Introduction

This chapter will explore the literature findings related to this investigation, beginning with the social aspects of death and caring for dying people, then move to the subject of paediatric palliative care where it will outline the differences between adult and paediatric palliative care. Descriptions of children's palliative care programs in existence around the world will be detailed. In addition staff, patient and family needs, and the locations where children's palliative care services may need to be provided will be examined, and details of 'best practice' will be discussed. The focus will then narrow to examine paediatric palliative care in Victoria, and finally the Australian standards for the provision of palliative care will be detailed.

2.1 Introduction, Social aspects of death and dying

In today's industrialised societies, the majority of people die in either hospitals or nursing homes (Fulton, 1972). Part of the reason for this is in the process of medicalising death and the care of those dying, and in the process confusing death with illness, hospitals, according to Blauner (1966), became mass care systems for the alleviation of pain, death, sickness independence and individuality in their patients. The average life expectancy in the industrialised world is now well into the eighties, making death primarily an experience of the elderly as over two thirds of deaths per year will occur in the over sixty-five years age group (Fulton, 1972). The institutionalisation of death into hospitals and nursing homes may have a sociological self-fulfilling prophecy effect as the increased separation of families from the dying individual reduces contact with the dying individual by family and friends, which may led to further 'mystification' of death. Along with this there is the societal perception that death has some form of stigma attached to it. When dealing with the death of children, the situation is compounded. For example Glaser and Strauss (1965b) argue that the younger and more socially and morally attractive the person who dies is, the more shocking and disturbing will be the impact of his/her death on those around them.

This was also observed by Sudnow (1967) who investigated the meaning of death to hospital staff, and found that the higher the perception of the patient's social value by hospital staff, the more effort and attention given to curative treatment modalities, and the more disturbed the relationships between health care professionals and their patients and families were. Often these relationships were socially ignored (Warren & Chopra, 1979). Conceptually, the role assumed by individuals who are sick has many problems. However there are several features that remain true, for example, dying is nearly always unscheduled and partly regulated and it is usually defined as undesirable and involuntary (Glaser & Strauss, 1965b). Staff expectations that the patients will be dependant and compliant and that they will participate in getting well, may lead health care professionals to see terminal patients as bad patients because they will not or can not get well. As a result health professionals have adopted avoidance and withdrawal strategies to overcome the dichotomy of emotional responses that caring for these patients arouses in them (Waechter, 1971).

The understanding of social and cultural responses to death is basic to any understanding of the broad organisational responses needed to improve the care of the dying individual. Most of the works in the literature do not draw attention to the social phenomena of caring for the dying in general, *let al.*one caring for dying children. Descriptions and analyses of caring for the dying individual have been undertaken in the hospital environment, however these are predominately with adult patients. For example sociological studies of dying and caring for dying patients rarely explore the 'lived reality' that needs to be organised by health care professionals and patients and their families as social beings. However it is the firm belief of this thesis that this exploration of 'lived reality' is especially important for children, as the time from classification as terminal or requiring palliative care may be extremely prolonged and the environment in which the patients and families exist will vary from institutional care to home care.

2.1.1 Research context of the present study

As stated earlier, it is the contention of this study that understanding social and cultural responses to death is vital to understanding the organisational changes that must occur to improve the palliative care of children who are dying. Much of the research that has been undertaken in the last thirty years or so into the phenomena of

death has been of a highly theoretical and abstract nature and has contributed little to our understanding of the needs of people caring for dying individuals. An exception to this has occurred in the research around an understanding of the sociological components of dying, where an understanding of the responses to death by hospital staff, families and patients themselves has been noted (Kellehear, 1990).

The present study addresses the understanding of the provision of palliative care to children, not only in an institutional setting but in the home setting as well. It is a phenomenological study which tries to describe in a broad sense, from the staff, patient and family viewpoint, the social processes involved in providing and receiving palliative care for children. The underpinning concept of this study's theoretical basis is that of the notion of a 'good death', an idea that is similar to that of a 'good life'. Both ideas have been used to describe forms of desirable conduct in various situations. Many societies have the notion of a 'good death'; for example the good deaths of Medieval heroes and explorers and military officers, and the rituals involved around the death bed in the Middle Ages, are typical illustrations. It is this 'good death' notion that provides a vehicle that will provide for comparisons between cultures, and is specific enough, whilst remaining broadly relevant, to allow for describing the various aspects of paediatric palliative care (Kellehear, 1990).

2.2 Paediatric palliative care

There is a striking lack of reportage in the literature relating to paediatric palliative care. Most reports are descriptive or uncontrolled evaluations of local services where patient numbers are usually small. It is suspected that this is due in part to practical, ethical and financial limitations.

The same difficulties are encountered when examining the general palliative care literature. There is very little evidence to support one model of care over another and investigations into cost-effectiveness have yielded inconsistent results. In critically appraising this body of work, Bosanquet and Salisbury (1999) came to the following conclusions:

> More rigorous techniques should be adopted in palliative nursing research, which combine qualitative and quantitative methods (p. 96)...
> ...there are few robust results and established findings to guide the decisions about funding or the management of services. The field of palliative care is

still to a great extent guided by general sentiment rather than specifically tested insights into how to develop more effective services (p. 213)... ...there remain some very important questions, which have been addressed by innumerable small descriptive studies with inconclusive results of limited generability (p. 214).

Whilst there is also little published material on the efficacy of hospice units within the hospital setting, there is however some debate about the usefulness of home death rates as a correlate of the efficacy of palliative care. Sirkia, Saarinen, Aldgren and Hovi (1997) have reported that 60% of families of children with malignancies in Finland have chosen to care for their child at home during the terminal phase. Lauer,Mulhern, Hoffmen and Camitta (1986) have reported a decrease in the number of hospital deaths and Goldman (1990) has similarly reported an increase from 30% to 70% of families of oncology patients at Great Ormond Street Hospital in London, who care for their child at home during the terminal phase of their illness. However there may be other, at present unrecognised, factors that have influenced this trend.

2.3 Definitions

According to the Shorter Oxford Dictionary on Historical Principles, the word palliate is derived from the Latin palliatus meaning 'cloaked' or 'concealed'. In more recent times it has come to mean 'to mitigate the sufferings of, to alleviate the symptoms of, to ease'. The World Health Organization (1998) defines palliative care as:

> ...the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families (p.5).

It is clear that not all patients who fall into this category of non-response to active treatment will die of their condition. In practice, most palliative care services are concerned with the care of dying patients, but children living with illnesses that are likely to cause death in the longer term, and even those with non-fatal chronic illnesses, could benefit equally from the application of the principles involved (Doyle, Hanks & MacDonald, 1993; World Health Organisation, 1998). Perhaps a more useful definition for those involved in the care of children is that devised by the Royal College of Paediatrics and Child Health (UK) in conjunction with the Association for Children with Life-threatening or Terminal Conditions and their families (1997):

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement (p.7).

The authors above, define a life-limiting condition as:

...one for which there is no reasonable hope of cure and from which children will die. Many of these conditions cause progressive deterioration (p.7).

There are two significant differences between the definitions above. Firstly, the WHO definition places emphasis on the concept of non-response to treatment thereby implying that for a patient to receive palliative care they must have had a 'curative' treatment option available to them. The second difference is one of extent of care, where the WHO definition makes no mention of the fact that patient and families may need respite care and bereavement care after the patient's death.

Palliative care and treatments aimed at cure or prolonging good quality of life are not mutually exclusive but each may take precedence at different phases of an illness. During the acute and chronic phases both curative and palliative care measures can be simultaneously active with each one potentially dominant at different times or stages of the child's illness. After death and in bereavement, palliative care measures become paramount. This can be represented diagrammatically, as in Figure 1.
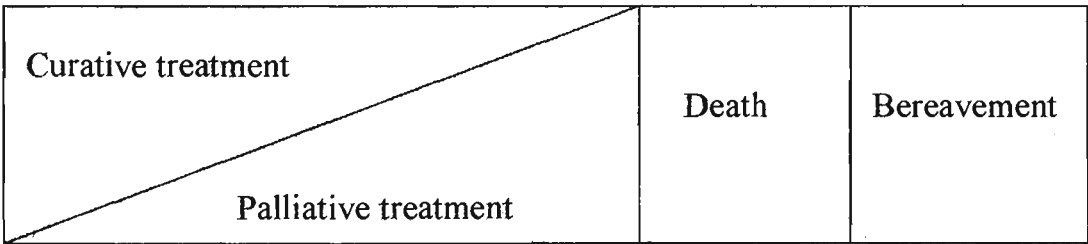
Figure 1. The complimentary relationship between curative / palliative support during the early phases of the disease, and the subsequent need for palliative support during death and extending into bereavement. (Adapted from: Frager, 1996)

2.4 Palliative care in the paediatric setting

Although the principles of palliative care apply equally to children, a number of fundamental differences affect their application in the paediatric setting. These differences are detailed below.

Paediatrics represents a smaller and more varied population in terms of the range of diagnoses encountered (Goldman, 1998). Palliative care services are provided primarily for adults with malignancies and fewer than 10% of patients in the care of adult palliative care services have other diagnoses (Palliative Care Australia, 1998). Bt comparison, in paediatrics, patients with malignancies comprise only about one third (30%) of the total number of patients. The major diagnostic groups in paediatric palliative care include:

- Malignancy
- Cystic fibrosis
- Metabolic conditions
- Neurological conditions (including Duchenne muscular dystrophy, cerebral palsy, Spinal Muscular Atrophy)
- Congenital anomalies (including cardiac anomalies)
- Immune deficiencies

Many of these conditions are rare and encountered only in paediatric practice. Some are familial, with the potential for more than one child to be affected in a given family.

In paediatrics the transition from curative to palliative care is often less clear (Frager, 1996; Robinson; Ravilly; Berde & Wohl, 1997) and the duration for which palliative care is required for children varies enormously. Palliative care may be required from days to years, depending on the underlying condition. For example, children with neurodegenerative conditions typically have a more protracted terminal phase than those with haematological malignancies (Sirkia et al., 1997).

Parents, as one would expect in the paediatric setting, are generally more involved as direct caregivers, (including some medical procedures) and are legal guardians and decision-makers (Finlay & McQuillan, 1995; McQuillan & Finlay, 1996). This

complicates decision-making and broadens the duty of care of palliative caregivers to include parents, siblings, and often, grandparents.

Developmental factors influence the child's understanding of illness and death, and ability to communicate and participate in decision-making, (Fleischman, 1994; Goldman, 1998) as well as their response to pain (McGrath & Craig, 1989). This varied understanding of the concept of death by children in differing developmental stages will impact on the way palliative care providers can relate to the children and their families. This implies that it is imperative that professionals involved in the care of children have a good understanding of these different concepts of death, and also, of how this can impact on them as caregivers. Play and educational activities are important considerations with regard to childrens' acceptance and communication of their feelings around their own or their sibling's death. This can have a considerable impact on their quality of life, and therefore these areas should be included in paediatric palliative care programmes (Goldman, 1998). Similarly, children differ from adults in terms of their physiology and pharmacodynamics and this has obvious implications for management (De Veber, 1993; Jacobsen & Koren, 1993).

Paediatric health care professionals develop long-standing relationships with children and their families and often wish to maintain their involvement during the terminal phase. As a result of this, they may be reluctant to hand over care to another clinician or service as often occurs in adult medicine. This reluctance to hand over care and continued involvement of the paediatrician may in part explain why aggressive attempts at cure are more likely in the paediatric setting (Morgan & Murphy, 2000). Conversely, the involvement of a paediatrician may have tangible benefits such as the improved management of symptomatology. In a recent study, lack of involvement by the child's paediatric oncologist in terminal care was a correlate of sub-optimal pain control (Wolfe, Grier & Klar, 2000).

Palliative care is now recognised as a specialist health care discipline. However when dealing with paediatric patients, the continued involvement of the acute health care team will have a great impact on the operation of palliative care services, with a collaborative model of care between the acute and palliative sectors being necessary.

Grief is generally prolonged following the loss of a child, and bereavement care may be required for extended periods. Often grief does not reach a peak until the second or third year following the death of a child (Rando, 1983). This has obvious implications for the provision of bereavement services.

The number of, and wide range of differences detailed above, indicates that services which provide palliative care to paediatric patients and their families need to acquire, or have access to resources that provide a degree of specialized knowledge about the theory and practice of paediatric medicine, psychology and sociology.

2.5 International models of paediatric palliative care services

There is no 'right way' to provide palliative care. Palliative care services have evolved variably within different countries to suit the structure of local health care systems, available resources and the local culture (Aranda, 1999). In the United Kingdom for example, religious and charitable organizations were responsible for the establishment of free-standing hospices, as Cicely Saunders said, '….in obedience to the Christian imperative' (Stoddard, 1979, p. 74). These institutions were designed to augment rather than replace existing health care services. In the United States however, where hospice has been regarded as a philosophy rather than a facility (Corr & Corr, 1985a), home care has been the focus of a movement led predominantly by nurses. This has implications for comparisons between different models of care and attempts to extrapolate results from one setting to another.

Many hospitals and health authorities around the world have dedicated palliative care services for children, with most of these provided to oncology patients. Disorders other than malignancies are not comprehensively addressed in either clinical practice or the literature despite the numbers of children dying of such conditions. These palliative care services can be broadly categorised into several areas which are noted below. Each category is illustrated by an exemplar service.

2.5.1 Hospital based programs
The Great Ormond Street Hospital for Children, Symptom Control Team, was established in 1986 and comprises three oncology nurses and a paediatric palliative

care physician with experience in paediatric oncology. Great Ormond Street Hospital for Children is a tertiary referral centre for southeast England and sees over 10% of the 1200 children in the United Kingdom diagnosed with cancer and leukaemia each year. The team is involved at all stages of the child's illness and focuses on symptom management, psychosocial support and community liaison. Home care is undertaken in the local area and 24 hour assistance is available. Since the introduction of the Symptom Control Team, the number of families choosing to care for their dying child at home has increased from 30% to 70 % (Goldman *et al.*, 1990).

2.5.2 Dedicated palliative care inpatient units

St. Mary's Hospital, Bayside, New York, has a palliative care service comprising a 10 bed inpatient unit, medical day care and a home care service provided for terminally ill children. Any child aged 16 years or less and with a life expectancy of less than 12 months, qualifies for assistance regardless of diagnosis. The unit provides medical and nursing care, pain management, allied health involvement, inpatient respite care, case management, social worker support, and pastoral and bereavement care. Home care is offered in New York City, Nassau, Suffolk and Westchester Counties and comprises symptom control, emotional support and pastoral care (Wilson, 1988).

2.5.3 Clinical nurse consultants in palliative care

The Royal Children's Hospital, Brisbane, provides two clinical nurse consultants in palliative care for oncology patients. Their responsibilities include coordination of patient care, staff education, and community liaison. Children with poor prognoses at diagnosis and those who have relapsed are referred early. Weekly palliative care oncology meetings centre around planning care for these patients. The low population density and large area served by the paediatric oncology service were factors in the team's decision to produce a booklet entitled *A Practical Guide to Paediatric Oncology Palliative Care* (RCH, Brisbane,1999), which is aimed predominantly at General Practitioners. Staff of the oncology unit make themselves readily available to community agencies for advice regarding management issues (Liebke, 1999).

2.5.4 Hospice facilities

Of the 23 paediatric hospices across the United Kingdom, the first, Helen House, opened in 1982. Its operation is illustrative of the way the other UK hospices function.

Most are charitably funded and are heavily reliant on volunteer staff. The philosophy of care is to create a 'home away from home' and to promote quality of life for dying children and their families. A homely environment is provided where parents and siblings may stay and participate in the care of their child if that is their wish. Respite is an important service provided by hospices and many families take the opportunity to rest and attend to the needs of their other children. Staff members adopt a flexible approach to care for their patients as at the parents' request. Direct medical care is usually provided by general practitioners. Bereavement support is generally provided for as long as the family requires it (Burne, Dominica & Baum, 1984).

2.5.5 Hospital-based community outreach programs

At the Children's Hospital, University of Helsinki, home care of dying children with malignancies is coordinated by the oncology ward with involvement of medical and nursing staff familiar to the child. A clinical nurse consultant, working alone or as part of a multidisciplinary team comprising a variable mix of doctors, social workers and other health care professionals, provides a number of services. The child is seen in the outpatient clinic while sufficiently well, and is visited at home later in the illness by medical staff. A rehabilitation nurse, social worker, psychologist and priest also provide support. Municipal home health care services are utilised for practical help at home as required. Following the introduction of the home care service, 60% of families have chosen to care for their dying child at home (Sirkia et al., 1997).

2.5.6 Community-based services

The Women's and Children's Hospital, Adelaide, has a full-time senior nurse providing palliative care support to staff and families throughout South Australia. Her responsibilities include education of hospital staff and regional care teams, attendance at oncology, bereavement and palliative care meetings, home visits, and coordination of home care. The service receives 40 referrals a year from a variety of units within the hospital. Home care is encouraged and supported through the availability of a 24 hour oncall nurse, involvement of general practitioners and meticulous attention to planning. Successful use has been made of tele-medicine in rural areas. The service is currently being evaluated (Fleming, personal communication, 1999).

2.5.7 Combination

In Melbourne, in 1983 the Royal Children's Hospital participated in a paediatric palliative care collaborative project between the Haematology/Oncology department of the Royal Children's Hospital and the Royal District Nursing Service (RDNS). The staff of the Haematology/Oncology department determined medical and nursing management, while the RDNS nurses received detailed referrals, attended weekly coordination meetings at the hospital and were available to families on a 24 hr basis, visiting children at home as required. In 1983, 21 children participated in the year-long project, 81% of whom died at home (Norman & Bennett, 1986).

2.6 Paediatric palliative care in Victoria

Palliative care services in Victoria are provided primarily for adults with malignancies and fewer than 10% of patients in the care of these services have other diagnoses (Palliative Care Australia, 1998). There are 40 services ranging from fully developed regional teams comprising palliative care physicians, nurses, psychologists, bereavement counsellors and volunteers, to single person operations (Australian Assoc. for Hospice and Palliative Care, 1995). Responsibility for this portfolio at a government level has been with the Minister for Aged Care, with Palliative Care Victoria and Palliative Care Australia as the professional bodies. No mention is made in the Palliative Care Australia publication, *Standards for Palliative Care Provision* (Palliative Care Australia, 1999) of paediatric needs or services.

There are three components that comprise palliative care services across Victoria. First, there are community-based palliative care services that care for a patient's needs in the home setting. Second, there are inpatient hospice units that provide care for patients that demand a higher level of care than that which can be provided in the home setting. Finally, there are acute hospital palliative care support beds that provide care for patients with high acuity in a secondary or tertiary hospital. In Victoria the appropriate level of care in a specific instance would be decided by the medical professional involved in conjunction with the palliative care service in question and the patient and family. A significant amount of work has been reported in the literature on the most appropriate setting for paediatric palliative care, and this will be discussed in section 2.7.

Continuity of care across all settings is strongly encouraged through joint staff appointments, care coordination, and facilitation of general practitioner involvement in all settings. There is also a commitment to education, training and research. Services are regionalized and in most cases all community-based services in a given region have amalgamated to form one legal entity, which holds a single service agreement with Human Services. In each region, all patients with palliative care needs are able to access the three components detailed above. Data collection, education and bereavement services are centrally coordinated but direct patient care is provided at multiple locations. Referrals go through the local palliative care provider according to the patient's place of residence. In some areas, there is sub-regional organization of care in that there are two or more legally constituted, area-based palliative care providers, each holding separate service agreements with the Department of Human Services. Services are then coordinated by a regional palliative care services advisory committee, and one sub-regional service generally acts as a lead agency in the administration of certain budget issues and the provision of information (Victorian State Government, 1997).

Staff working in adult palliative care services possess valuable skills in symptom control, family support and an emphasis on quality of life, but they usually lack experience with children (Frager, 1996). In other countries, parents of dying children have been reluctant to use community agencies because of a real or perceived lack of experience with paediatric issues and procedures as well as an unwillingness to work with unfamiliar staff (Lauer *et al.*, 1986; Sach, 1997). The experience of palliative care services shows that while families may benefit from the input of an adult specialist palliative care team, there is a need for education and close liaison with paediatric staff (Finlay *et al.*, 1995; McQuillan *et al.*, 1996; McKeogh & Evans, 1996). In Melbourne, few children are cared for by community palliative care teams. Reasons for this include a reluctance by paediatricians to refer, lack of awareness of the services available, and parental concern regarding the ability of such teams to adequately care for their child (Sach, 1997).

2.6.1 Very special Kids Inc. (VSK)
Very Special Kids is an organization that exists outside the mainstream health care services and operates Very Special Kids House, Australia's first respite care and

hospice facility for children. VSK was founded in 1985 and offers a mix of support from professional staff members and a network of 200 volunteers. Currently VSK offers support to 560 families throughout Victoria. The eight bed hospice is situated in Malvern, an inner eastern suburb of Melbourne. Medical support to VSK is provided by a local general practitioner. VSK is funded through philanthropic grants and public donations and receives support from the Victorian Government in the form of grants (25% of running costs), and property, as the VSK house facility is built on land leased from the government for a minimal lease fee. There is no charge for families to utilise VSK house and families may stay as often and as long as they like (Very Special Kids, 2002).

VSK house is utilised primarily by families of children with neurodegenerative conditions for respite care, a situation in common with similar hospice facilities in the UK (Burne *et al.*, 1984; Goldman *et al.*, 1990). In reality, families are granted only short stays at the house due to small bed numbers (eight beds) and a large clientele; however patients who are clearly terminal, and their families,can be accommodated for much longer periods. To date (2002), there have been few deaths of children whilst actually in VSK house.

2.7 Location of palliative care

Adult palliative care is generally carried out either at home or in a hospice or hospital setting. The discussion below presents some of the findings of a range of investigators who have considered the factors contributing to the most appropriate setting for paediatric palliative care.

2.7.1 Home

Generally it has been found that families prefer to care for their sick children at home for five identifiable reasons. First, there is a perceived need for a familiar environment, where the family's routines are not dictated to by the schedules encountered in a hospital setting, thus allowing fewer disruptions to the normal pattern of living (Kohler & Radford, 1985). Second, caring for the child at home allows for greater freedom to involve the extended family and friends in the care of the sick child (Goldman, 1995). Third, the home setting allows more opportunity to the parents to attend to the needs of the child's siblings, and to involve them in the

care of the sick child (Lauer, 1997). Fourth, control over post-death events is facilitated by the family being at home and not being subject to hospital protocols and routines (Darbyshire, Haller & Fleming, 1997), and lastly, the family home provides privacy for the family and child to go through the terminal phase of the illness in their own unique way, and not be manipulated by health professionals who subscribe to particular views on how dying should be accomplished (Vickers & Carlisle, 2000).

Up to 80% of families will choose home care if a support service exists and is offered (Lauer et al., 1986; Sirkia et al., 1997). There is some evidence that long-term adjustment is better in this group with a more rapid return to previous home, work and social involvement and a lower incidence of pathological grief reactions (Lauer et al., 1983; Lauer et al., 1986; Lauer et al., 1989; Mulhern, 1983). Whilst parents generally describe the overall experience of nursing their sick child as a positive one (Sirkia et al., 1997; Lauer et al., 1980; Vickers et al., 2000), caring for a sick or dying child at home is an enormous task and presents a number of difficulties. Parents cite exhaustion, difficulty reconciling their dual roles as parents and 'nurses', and financial burden as barriers to their ability to carry out this task (Darbyshire et al., 1997). There is often anxiety over symptom control and terminal events, which may precipitate presentation to the emergency department especially in situations where community supports are poor (Kohler et al., 1985; Sirkia et al., 1997; Darbyshire et al., 1997).

Institutions offering their own services to children at home have a higher utilisation rate and lower readmission and hospital death rates than those relying on community-based services (Lauer et al., 1986; Chambers, Oakhill, Cornish & Curnick, 1995). Although parents are comforted by the availability of 24 hour support, most visits by home nurses occur during normal working hours (Norman et al., 1986).

The key elements of an effective home service have been described by Chambers et al., (1995) as:
- cessation of cure-oriented treatment.
- a desire for home-care by both parents and child.
- maintenance of an open-door policy by the hospital.

- 24 hour access to medical and nursing support.
- access to psychological and bereavement counselling.

Most symptoms including severe pain, haemorrhage, seizures and respiratory distress can be adequately managed in the home environment with appropriate support (Lauer *et al.*, 1980; Chambers *et al.*, 1989; Sirkia *et al.* 1998). The aim of home care is to allow the child to spend as much time at home as possible, recognising that many families will wish to return to the hospital close to the time of death (Whittam, 1993; Sirkia *et al.* 1997). However, according to Lauer *et al.* (1986), the following interventions are associated with a lower rate of readmission of children dying from malignant conditions:

- regular home visits.
- use of paediatric oncology nurses to provide care.
- utilisation of a home care manual.
- formal home care policies and procedures.
- use of institution-based services.

The general practitioner and community paediatrician are important in providing clinical and emotional support to the family at a local level. Unfortunately, tertiary institutions often foster dependence and exclusive reliance on their services and staff (Kelly & Hewson, 2000). Stevens and Owen (1987) observe, in relation to this relationship:

> Treatment often lasts several years, and the parents and children become completely dependent on the regional centre for medical care and emotional support, during which time the district paediatrician and family doctor become strangers to the child, the family, and the illness (p. 1548).

The importance of maintaining links with the general practitioner throughout the child's illness cannot be over-emphasised. This increases the general practitioner's likelihood of being involved in terminal care (Chambers *et al.* 1995). Some units have found that the distribution of information packages, that contain information regarding the diagnosis and treatment of the condition, as well as contact details of the relevant staff, to general practitioners at the time of diagnosis to be very useful (James, Harris, Mott & Oakhill, 1988).

2.7.2 Hospice

It has been emphasised by proponents of the hospice movement that it is 'a philosophy, not a facility' (Corr & Corr, 1985a) and it shares the same goals as those of palliative care. However the Royal College of Paediatrics and Child Health (1997) states that adult hospices are not considered appropriate settings for paediatric patients. Paediatric hospice facilities are used mainly by families of children with neurodegenerative conditions for respite rather than terminal care (Burne *et al.*, 1984; Goldman *et al.*, 1990). The provision of respite is an important aspect of care and aims to encourage family unity, avoid social isolation and prevent exhaustion. This however, depends on staff competence and knowledge of the child and family (Farrell, 1996). Some families are unable to accept respite care in these facilities due to the distress they experience when surrounded by other terminally ill children (Stein, Forrest, Woolley & Baum 1989).

Following a recent and rapid increase in the number of paediatric hospices in the United Kingdom, there has been considerable debate about the need for such facilities and whether funds are better spent improving home care services for children with palliative care needs (Chambers *et al.*, 1987; Goldman, 1995).

2.7.3 Hospital

Parents usually choose hospital care for their child because they are unable to deliver the care required or are anxious about symptom control and terminal events. Others seek a familiar and secure environment, where they feel their child can receive expert care and symptom management (Lauer *et al.*, 1980).

Studies of the needs of families in the hospital situation have been carried out but it is difficult to extrapolate findings from one environment to another (Ashby, Kosky & Laver, 1991). In very general terms, families require private areas where they can communicate with each other and with health professionals, and telephone facilities where they cannot be overheard. A flexible and sensitive approach to viewing of the child's body after death, and organization of funeral arrangements is also required.

Communication between hospitals and community services is often perceived as poor and emergency admission procedures are seen as slow and frustrating by families (Sach, 1997).

Hospital staff may make decisions for parents based on their perception of the family's needs and wishes as well as a limited understanding of the community services available (Lauer *et al.* 1986). Often this decision is based on the hospital staff's assessment of family structure, function and socio-economic status. Family characteristics such as socio-economic level and stability are poorly predictive of a family's ability to provide home care (Lauer & Mulhern, 1984). Families should be made aware of all options by hospital staff so they can choose what is appropriate for them. They should also be able to change freely from one option of care to another. In circumstances where symptoms cannot be controlled adequately at home or are causing concern for the child and family, expeditious readmission should be possible (Vickers *et al.*, 2000).

2.8 Patient and family needs

A considerable body of qualitative research exists into the needs of families caring for a child with a life-threatening condition (Wallace, 1995; Sach, 1997; Darbyshire *et al.* 1997), and includes studies of patient populations representative of or comparable to those seen at the Royal Children's Hospital (Sach, 1997). In formulating the *Guidelines for the Development of Children's Palliative Care services in the United Kingdom,* it was the view of the working party that such research did not require duplication or local validation (Royal College of Paediatrics & Child Health, 1997). Patient and family needs cannot be addressed in isolation as each affects the other. For example, a child's pain can heighten parental anxiety, and conversely, family distress may adversely affect pain perception by the child resulting in poor pain control.

2.8.1 Symptom control

Symptoms encountered in paediatric palliative care vary according to the diagnosis. In a recent retrospective series, 89% of paediatric oncology patients were reported by their parents as having suffered 'a great deal' from at least one symptom during their

terminal phase (Wolfe *et al.*, 2000). In oncology patients, pain is by far the most common symptom and occurs in more than 75% of patients (Goldman *et al.* 1990; Wolfe *et al.* 2000) whilst anorexia occurs in 50% (Kohler *et al.* 1985), and dyspnoea in 40% (Hain, Patel, Crabtree, & Pinkerton, 1995; McQuillan *et al.* 1996). Other symptoms, which occur in this group of patients, and which need to be regarded as a serious or emergency event, include nausea and vomiting, fatigue, diarrhoea, constipation, incontinence, seizures, insomnia, and bleeding (Chambers *et al.* 1989). In neuro-degenerative conditions, issues relating to mobility, increased secretions and nutrition predominate, with respiratory symptoms also being common (Hunt, 1990; Hunt & Burne, 1995). Control of distressing symptoms is extremely important and access to medical and nursing expertise must be available 24 hours a day, regardless of the place of care. Pain in particular should be regarded as an emergency, as patient and family coping mechanisms fail quickly when the child is perceived as being in pain (WHO, 1998).

The first step in addressing symptoms is to recognise them, and one cannot rely solely on families to volunteer this information. There needs to be an ongoing assessment of the child's condition by health professionals from a variety of disciplines. An appreciation of how the symptoms affect the child and family's functioning is also important and due consideration should be given to the factors contributing to the symptom (Frager, 1996). For example, fatigue may be accepted as an unavoidable result of tumour progression, or seen as a potentially ameliorable problem related to such factors as anaemia, depression and poor nutrition. The needs of some children with life-threatening conditions are growing increasingly complex and may include such interventions as home ventilation (Campbell *et al.* 1998).

2.8.2 Emotional support

Nursing staff engaged in the support of families undertaking home care can expect to spend most of their time providing emotional support (Norman *et al.*, 1986). As well as dealing with complex emotional and psychological issues, children with chronic illnesses are at increased risk of behavioural and emotional disturbance (Stein *et al.* 1990). In a recent study of the experiences of children with terminal malignancy, 63% were described by their parents as 'not calm' and 21% were said to be frankly 'afraid' (Wolfe *et al.* 2000). Parents often suffer depression, social isolation and marital

dysfunction with adjustment difficulties more likely in women, parents aged over 35 years, less cohesive families and in circumstances where the diagnosis was made less than two years previously (Mastroyannopolou, Stallard, Lewis & Lenton, 1997). Those with previous social or psychological disturbance are also at increased risk of family dysfunction more than 12 months into bereavement (Jurk, Ekert & Jones 1981). Little is known, or written, about the needs of grandparents, and it is suggested that this area needs careful research.

Families often benefit from contact with others who have been through similar experiences (Collins, Stevens & Cousins, 1994). Well siblings may feel isolated and unable to express their distress for fear of upsetting their parents. Consequently, they may either fail or overachieve at school as a result. In addition behavioural problems, psychological disturbance and psychosomatic complaints are not uncommon (Pettle & Lamsdowne 1986; Sloper, 1996). In one study, 98% of siblings reported a negative impact on their life, yet less than half had shared this information with anyone (Stallard,Mastroyannopolou, Lewis & Lenton, 1997). Siblings appear to benefit from consistent information and involvement in the care of the affected child particularly in the home environment. There is also some suggestion that peer support programs such as the 'Good Grief Program' in Melbourne may be effective (Tonkins & Lambert, 1996).

2.8.3 Information

The patterns of communication established at the first interview are vividly recalled by parents, and influence the working relationship between doctor and family (Woolley, Stein, Forrest & Baum, 1989a; Stevens, 1993). Whilst parents appreciate openness, privacy, sympathy, time and repetition of information (Sloper, 1996), they do not like evasive behaviour, interruptions and the presence of staff they do not know (Woolley *et al.* 1989a). Accurate, up-to-date information regarding prognosis and what to expect at the time of death and beforehand is desired, as this helps parents make decisions and plans (Ashby *et al.* 1991; Sach, 1997). Although parents express a desire for honesty, it is important for this to be tempered with a sense of hopefulness (Jefidoff & Gasner, 1993). However, in practice this balance is difficult to achieve with reports of gross discrepancies between the prognostications of physicians and

parents, with the latter often being considerably more hopeful. Importantly, physicians are often unaware of this discrepancy (Mulhern, Crisco & Camitta 1981).

Parents may need help negotiating 'the system' (Darbyshire *et al.* 1997). They perceive the acquisition of information regarding their child's illness and the services available is slow and demanding and often comes from other parents. Time is especially valuable to them and they would rather spend it with their child (Sach, 1997). Information is now readily available, to parents, via the Internet. Families may find it difficult to interpret this information however as its accuracy and scientific validity may be questionable, and as parents and families often do not posses the knowledge to critically assess what they have accessed, they may become confused about treatment options and prognosis.

2.8.4 Practical assistance

Aids such as sheepskins, wheelchairs and bed-pans are commonly required, as are infusion sets, pumps and medications. Obtaining these items can be a tedious and expensive task (Collins *et al.* 1994; Sirkia *et al.* 1997). Respite is commonly needed (Jefidoff *et al.* 1993; Wallace & Jackson 1995), but difficult to obtain, particularly if trained carers are required or night-time care is needed (Collins *et al.* 1994; Sach, 1997). For parents to benefit from respite care, they must feel confident that the standard of care provided is high (Farrell, 1996). Respite may be provided in either the home, hospice or hospital.

2.8.5 Financial assistance

Many families incur a substantial financial burden as a result of their child's illness, particularly if they decide to care for the child at home (Wallace *et al.* 1995; Sach, 1997; Deeley, Stallard, Lewis, Lenton, 1998). At least one parent often leaves paid employment to care for the child, with the other reducing working hours significantly (Darbyshire *et al.* 1997; Mastroyannopolou *et al.* 1997). Combined with this are the costs of equipment, medications and nursing. Most families in Australia with a child who has complex health care needs, qualify for Government Health Care Cards, which reduce these costs. In addition, some patient groups may be able to access charitable funds for the provision of aids and other requirements.

2.8.6 Attention to quality of life

With such a plethora of issues to attend to, factors that may significantly enhance a child's quality of life are often forgotten. In a recent study of the experiences of children with terminal malignancy, 53% were perceived by their parents as 'having little or no fun' (Wolfe *et al.* 2000). Care is needed in applying one's own standards to assess another's quality of life, but in childhood, activities such as play, attendance at kindergarten or school, and visits from friends are likely to be important. In adolescence, ongoing participation in peer-related activities and some degree of independence are factors that need consideration (Carr-Gregg, Sawyer, Clarke & Bowes, 1997). Because of the importance of ensuring that the child's quality of life is at least maintained, there needs to be further consideration given as to how palliative care services can contribute in this area. The work of Wolfe *et al.* (2000) and Carr-Gregg *et al.* (1997), whilst contributing significantly to this question through their choice of methodology and sampling, were carried out in an environment somewhat culturally different from that of the RCH. This difference suggests that there may be some useful information obtained from a partial replication of these works in an Australian paediatric setting.

2.8.7 Care planning, coordination and decision making

A proactive approach in planning patient care may avoid the family lurching from one crisis to another (Ashby *et al.* 1991; Frager, 1996). The anticipation of potential crises (eg. seizures, respiratory failure, haemorrhage) and their discussion with the patient and family, may allow decisions to be made in advance regarding treatment plans, and may also avert the trauma of a futile resuscitation attempt (Parker, Maddocks & Stern, 1999). However, children and their parents may wish to change their minds regarding such decisions at any stage. In retrospect, they need to know that everything that could be done was done (Jankovich, 1989; Vickers *et al.* 2000). They may also need time to accept the inevitability of death.

Having formulated a treatment plan, in conjunction with the medical team, there are a number of ways in which this may be communicated to those responsible for performing care. This communication needs to be accomplished in various forums. Firstly, a letter or proforma, detailing treatment choices made by the patient, family

and treating team in collaboration should be given to the family, with a copy prominently placed in the child's record. Further copies should be sent to other services that may be involved in the care of the child and family in different settings, for example the child's general practitioner or visiting homecare nurse. Secondly, documentation of expected responses by health professionals should also be detailed in written form with a copy in the child's record. This can do much to alleviate patient and family stress when significant changes occur in the child's condition. Finally, these matters need effective verbal communication to health professionals involved in the direct care of the child so that continuity of the plan is assured (Darbyshire *et al.* 1997).

It has been observed that raising the above issues when things are going well is exceedingly difficult but potentially beneficial in the long-term. The process of care-planning for the family and child requiring palliative care, needs to be handled sensitively and with professional guidance so that decisions made are joint ones. It is unfair to expect parents to take sole responsibility. By sharing expertise and experience, the physician may facilitate a course of action that promotes the child's best interests (Fleischman, 1998). In most cases, whilst such decisions are clear and collaborative, in some instances conflict may arise between medical staff and family members. In these circumstances, seeking a second opinion from a colleague may be useful. In very difficult cases, consultation with an ethics committee or patient advocate may help mediate disputes and protect the interests of the child (Fleischman, 1994). Health care professionals often use their own frame of reference to evaluate the quality of life of their patients. This is especially true in paediatrics where very young children cannot communicate what is important to them. It is often said that good ethics starts with good facts, and the presentation of information to families may be coloured by what the health professional feels is best for the patient as well as by his or her own prejudices regarding treatment options (Hilton, Orr, Parkin & Ashwal, 1993). How facts are presented is just as important as the facts themselves. The importance of a clear plan of action in reducing patient, family and staff stress at times of significant change in the child's condition can not be over emphasised. Whilst the earlier works of Ashby *et al.* (1991), Frager (1996) and Vickers *et al.* (2000) have contributed a significant insight into this, only Ashby's work was

undertaken in an Australian setting. This suggests that there may be useful information obtained by a further examination of this question.

The large number of services involved in managing children with palliative care needs suggests the need for meticulous planning and coordination to ensure appropriate service delivery and continuity of care. Parents often find it difficult to locate and coordinate community services, and the utilisation of 'key workers' or 'case managers' has been successful in other care settings (Woolley et al. 1991). This 'key worker' might be a general practitioner, paediatrician, nurse or allied health worker.

2.8.8 Time of death

Parents may seem very knowledgeable about their child's illness and the treatment involved, but they have generally not experienced the death of a child. Most will benefit from sensitively delivered factual explanations of terminal events such as respiratory changes, incontinence and the rigidity which evolves after death (Darbyshire et al. 1997). This may avoid anxiety and help the family position the child's body in an acceptable way after death.

Most parents will want to spend time in a quiet, private area with their child after its death (Ashby et al. 1991). Many parents wish to bathe and dress their child, and most desire mementos such as lockets of hair and photographs (Stein et al. 1989; Dent, 1996). Some parents may wish to take the child's body home with them, in which case arrangements need to be made to ensure preservation of the body, for example cooling of the house.

Palliative care staff need access to information regarding cultural and religious issues which may influence their management of the child's body and the grieving family (Stevens, 1993). It is important however, not to broadly categorise families according to ethnicity or religion, as there is considerable variation regarding the nature and strength of beliefs and customs.

2.8.9 Bereavement care

Grief is a normal process and while most families do not require specialist help to cope (Royal College of Paediatrics & Child Health, 1997), they may however benefit

from reassurance that the thoughts and feelings they are experiencing are not abnormal. Grief following the loss of a child is longer than that which follows the loss of an adult and may increase in intensity in the second and third year of bereavement (Rando, 1983). Adjustment difficulties are more likely following a short illness in the child who has died (Collins *et al.* 1994). Continuing contact with hospital staff is very important to parents who often fear separation from those they have come to know and trust (Ashby *et al.* 1991), and condolence cards and attendance at the child's funeral by health care professionals are greatly appreciated by parents. Bereavement care needs to be comprehensive, identifying those at risk and providing expert counselling if required (Lauer *et al.* 1997). Grieving families are generally not in a position to judge their need for professional counselling, many do not know how to access appropriate assistance, and some cannot afford the services available. There has been a general failure of tertiary institutions to take responsibility for bereavement care (Whittam, 1993), and where hospital-based support groups are offered, some families find it difficult to return to the institution and others do not find group activities helpful. Whilst most bereavement support is targeted at the parents, sibling bereavement needs are not adequately addressed (Sach, 1997), and there is little research into the effects of childhood death on grandparents and the extended family.

Parents find a follow-up appointment with their child's paediatrician constructive and helpful (Jankovich, 1989), but they may need encouragement to attend. In one study, where parents were telephoned by the paediatrician two days after the child's death, 89% agreed to, and attended, a meeting with their child's consultant physician (Jankovich, 1989). Points of discussion at this follow up may include a review of the child's illness, care and death, interpretation of post-mortem results and alleviation of parental guilt (Newton, Bergin & Knowles, 1986; Williams, 1963). Clinicians are ideally placed to provide counselling on bereavement to parents and siblings, but in most cases their training in this regard is inadequate.

The importance of a continuous plan of care through the terminal phase of a child's illness and extending into the bereavement phase has been well established by the work of Ashby *et al.* (1991), Darbyshire *et al.* (1997) and the Royal College of Paediatrics and Child Health (1997). However, these studies were all performed from

the perspective of the family, and useful information on this area will be obtained by a further examination of these questions from other perspectives.

2.9 Staff needs

There is a generally held belief in Western society that the death of a child is unnatural, and it is an expectation that children will outlive their parents. This expectation can, and does, often lead to a sense of failure among professional carers when a child dies (Wooley *et al.* 1989b). To buffer this feeling of inadequacy, professionals develop strategies to help them cope, and prominent amongst these strategies is distancing. Waechter (1971) reported that as a patient's death became more imminent, the number and length of contacts made by nursing staff engaged in their care decreased, Davis (1996) supports this assertion in a later study. It has also been reported that nurses who have developed a personal involvement with a patient, such as is likely to happen in situations involving children with a long term, progressive, potentially fatal illness, may have greater difficulty providing palliative care in the terminal phase of a patient's illness (Glaser & Strauss, 1965a; Quint, 1967; Vachon, 1987).

Stress amongst staff who provide palliative care for children, in any setting, is likely to be great, and the stresses involved in providing palliative care for children may affect the caregiver's ability to provide care in a sensitive and professional manner (Potter, 1982; Wheeler & Foester-Lange, 1985; Lattanzi, 1985; Lattanzi- Licht, 1991; Papadatou, 1991). Cynicism, social withdrawal, resistance to change and physical symptoms are manifestations of 'burnout' (Stein & Woolley, 1994). Regular supervision and access to professional expertise by staff in areas where long-term relationships with patients and families occur, are important and should ideally be written into job descriptions (Royal College of Paediatrics & Child Health, 1997).

Professionals dealing with palliative care and death in children require a special sensitivity to caring and greater maturity, in that they must be well in touch with their own feelings and humanity before they can offer support to families and children (Farrow, 1981). Such professionals must be mature, stable, and have specialized paediatric and palliative care experience (Wilson, 1985). High patient acuity levels, inexperienced or changing staff within the unit, low staff numbers, and a philosophy

of care that stresses curative goals, can all increase staff stress levels. Clearly focusing nursing care on palliative, rather than curative goals, can be of assistance in reducing stress levels among nurses engaged in providing care (Eakes, 1984).

There are a number of ways in which staff may be supported. Formal support through regular team meetings reduces conflict between staff members as long as open discussion is encouraged, and this is critically dependent on the structure of the team. Formal support at an individual level is beneficial for some. It is particularly useful in circumstances where concerns can not be raised in the group context. Informal peer support is generally regarded by staff as most effective (Woolley *et al.* 1989b). Supervision may assist in developing the self-awareness necessary to achieve maintaining perspective through involvement in outside activities. Education provides staff with the skills they require to overcome feelings of impotence. In a recent survey of resident medical officers in the United Kingdom, lack of training in the breaking of bad news was identified as a serious deficiency in their education (Dent, 1990).

2.10 Best practice

There is little in examining the literature to promote one model of care over others, but the components of best practice are summarised in the publication *A guide to the development of children's palliative care services in the United Kingdom* (Royal College of Paediatrics and Child Health and the Association for Children with Life-threatening or Terminal Conditions and their Families, 1997) as:

- Assessment and frequent re-evaluation of individual patient and family needs with the formulation of a care plan.
- The use of a key worker to coordinate care.
- The involvement of a consultant paediatrician expert in the child's condition.
- The involvement of local clinicians, nurses and therapists skilled in children's palliative care.
- 24 hour support of families in the management of physical and emotional symptoms.
- Regular respite care.
- Emotional support of parents and siblings during both the child's illness and bereavement.

- Provision of medications and aids.

- Provision of housing adaptations and equipment for use at home and at school in a timely manner.

- Financial guidance and assistance.

To this can be added (Frager, 1996)

- Staff support.

- Involvement of staff with expertise in ethics.

- Education for both medical and lay populations.

- School visitation programs.

The International Work group on Death, Dying and Bereavement, emphasises the need for early identification of children with palliative care needs, and the institution of 'an individualised, coordinated system of care, which provides continuity of services between the hospital, the home and the community' (International Work group on Death, Dying & Bereavement, 1993).

2.10.1 Standards for palliative care

Palliative Care Australia (1999) has formulated and published *Standards for Palliative Care Provision* to guide practice in Australia. These are organised according to six domains, or areas of care (Palliative Care Australia, 1999) which are: physical, psychological, social, spiritual, cultural and structural. However, while these domains address the needs of adults, there is no mention of paediatric or age-related needs or of developmental issues that may relate to the delivery of palliative care to patients. The International work Group on Death Dying and Bereavement (1993) has argued that paediatric palliative care services should be:

> An individualised, coordinated system of health care which provides continuity of services between the hospital, the home and the community [and] must be developed as soon as feasible after diagnosis...maintained throughout the illness and death with support for family members after the death...and accessible to all children and their families regardless of race, sex and culture (pp. 277-280).

2.11 Summary

Paediatric palliative care is a relatively under-researched area, that has significant differences from the notion of palliative care that is utilised in caring for adult patients. The differing developmental stages, physiology, communication and

emotional responses exhibited by children affect the way in which palliative care services interact with them and with their families.

The spectrum of paediatric patients that require palliative care is quite different from that found in adult medicine, with a much larger representation of patients with chronic disease. This has obvious implications for the timeframe that palliative care agencies need to provide services.

The continued involvement of paediatricians, because of the different physiological requirements of children, necessitates a collaborative model of care that is unlike the current 'handover' model that adult palliative care services utilise.

Lastly, parental perceptions of lack of experience and expertise, in pediatric palliative care issues, of community based health professionals, and a parental unwillingness to become involved with unfamiliar staff may, as reported by Lauer *et al.* (1986) and Sach (1997), lead to a reluctance by families to engage with community based agencies. Similarly, a perception by paediatricians of lack of experience in pediatric care by community based agencies may lead to a reluctance to refer patients to them.

Despite this, however, there are models of paediatric palliative care delivery that are in use around the world, but there is little or no research to recommend one above the other. Few, if any large-scale systematic reviews have been undertaken of paediatric palliative care programmes.

The next chapter will detail the theoretical framework(s) that underpin this research and provide details of the developmental theories of Piaget and others. The focus then moves to examine the development of theories on death and dying, and their applicability to the paediatric setting.

Chapter 3 Theoretical framework

3.0 Introduction

Whilst there has been recent attention focused on the care of dying patients and their families (Bluebond-Langer, 1978; Corr & Corr, 1992 a & b; Copp, 1996), and this area does indeed remain of interest to researchers, there have been limited attempts to critically explore theories of death and dying to promote our understanding of this area.

Of significance to this investigation has been the fact that there has been no attempt at any time to explore the care of children and their families who have a life-limiting illness. Before any attempt to understand the interactions around the care of dying children and their families, it is instructive to understand the way in which children interpret and make sense of the world around them.

This chapter will examine in detail some of the major theoretical frameworks related to child development, and review a number of theories of dying that will underpin and provide the context for this research. It will finally outline the specific framework used in this study.

3.1 Developmental theories

Young children think in a different way to adults, and an understanding of these thought processes is critical to communicating with them (Nagy,1996). It will be the contention of this study that when working with children it is essential to understand everything about them; how they play, the way that they deal with stressful situations, their understanding of the way their bodies work and how they become sick, how they conceptualise death, and their understanding of the differences between right and wrong. To make matters more complex, the realities of a child differ at differing ages. To help in this regard, a number of theories have been advanced over the years to explain the nature of psychological development in children. Chief among these are the theories of Freud, Erikson and Piaget, where each of these authors saw development as proceeding in a series of stages.

Freud (1964) believed that sexual drive had an enormous influence on the emotional development of children. He described five psychosexual stages, each of which was based on the area of the body that is the primary source of pleasure at a specific age. Freud's theory is known as the psychoanalytic approach, and although his ideas have been the subject of much criticism, they remain highly influential in the development of modern psychology. Freud described five stages in the development of personality; (1) oral, (2) anal, (3) phallic, (4) latency and (5) genital. Along with these stages, Freud also believed that there were three components to personality; id, ego and superego, that develop as the child matures. These components of the personality work together in a kind of psychic conflict, each aiming for expression. Ideally the balance of power between them should be roughly equal, so that we, as individuals, can maintain a reasonable balance between serving our own needs and those of the society that we live in.

Erikson (1963) felt that development was a function of children's social relationships and occurred in a series of eight psychosocial stages, that occurred throughout life. Differing from Freud and Piaget, Erikson, extended his ideas into old age. Erikson was influenced by Freud's ideas, but departed from them in that he emphasised the importance of social relationships as the basis for development rather than psychosexual conflict. He believed that at each developmental stage, the child must undertake a specific psychosocial task, or confront a crisis, involving the relationship between the inner psychological self and the external social world. These tasks or crises could be resolved positively or negatively; however Erikson claimed that the more positive the outcome at each stage the better equipped the child was for negotiating the next stage of development.

Piaget (1954) focused on the development of childrens' cognition. He closely observed the cognitive development of his three children, and described four stages, which he believed characterised the progression from infancy to adulthood. As a result of these observations, Piaget believed that intelligence is the ability to adapt to new experiences. He argued that children are continually trying to make sense of their experiences and achieve a state of mental equilibrium in one of two ways. Firstly, children can interpret new experiences to fit in with the way they already understand their world. Piaget called this process assimilation. In parallel with this, he also

reasoned that children could change the way that they think to accommodate new information or experiences. He labelled this process accommodation. Piaget believed that as the child's mental structures develop, they continually reconstruct the way in which they understand the world until their understanding reaches the sophistication of adults. Piaget described four stages of cognitive development; sensorimotor, pre-operational, concrete operational and formal operational through which children, using the processes of assimilation and accommodation, understand their world. His work is of great benefit in helping us understand the way in which children think, and in the context of this study further exploration of how his work relates to the four stages of childhood is warranted.

3.1.1 Infancy

Piaget's first stage of cognitive development, the sensorimotor, lasts from birth to approximately two years of age, it could be postulated that the young infant does not think in any conventional sense in this stage but rather reacts reflexively to changes in the environment as perceived through its senses. As the child's mental structures develop and its experience of the world increases, the quality of its thinking will also change. The infant comes to understand its own helplessness, and that its comfort and survival depends on the care which is given to it, usually by its parents. This relationship between the infant child and caregiver is essential for its physical survival and for long term emotional, social and intellectual health. Whilst 'bonding' and 'attachment' are two terms often used interchangeably to describe this relationship, these are not synonymous terms. Bonding refers to the commitment that develops in parents towards the child, whereas it is thought that attachment refers to the reciprocal affection between parents and children. Bonding is a process that begins soon after birth, but it is observed that infants do not begin to show signs of attachment until around six months of age (Bowlby, 1975; Klaus & Kennel, 1976).

Older infants frequently show fear of separation from the person that they have come to rely on for their survival. This reflects Piaget's ideas in that the infant has learned who is necessary for its comfort and survival and that separation from that individual will have adverse effects on it.

The infants' concept of their body image is largely undeveloped, it is thought that they learn about their bodies through being handled, through their own movements and through somatic experiences such as thirst, hunger comfort, discomfort and pain. The sense of being separate from their environment is learned through the first year of life, probably again from their being moved and observing the departure and return of others. Through such experiences, infants learn to conceptualise themselves as having a separate existence.

Although infants cannot comprehend the meaning of death, they can be very much affected by a death in the family. For example, if parents are grieving, infants can detect their sadness and be affected by it. To experience grief, an infant must have developed the concept of 'object permanence' and be capable of experiencing separation anxiety (Nagy, 1996). Object permanence is a concept described by Piaget as the understanding that objects that cannot be seen still exist, and he believed that developing this concept was a major cognitive task faced by infants. Some infants show the beginning of object permanence as young as four months of age, whilst most infants have some understanding of it by eight months although it may not be fully developed until around eighteen months of age (Diamond,1982).

Infants may therefore be capable of grieving long before they can understand the concept of death or are able to verbalise their distress. As a result infants and small children may be regarded as too young to be affected by deaths around them and their need for comfort and support may go unrecognised by adults who are also highly distressed and grieving (Raphael, 1983).

3.1.2 Early childhood

Early childhood involves the second of Piaget's stages of cognitive development, the pre-operational stage. Pre-operational thinking is characterised by certain features that account for many of the misconceptions that young children have about events in the world. Pre-operational children have difficulty understanding that objects may change their appearance, but not their nature. They also have difficulty in understanding the concept of time. One striking characteristic of the pre-operational child's thinking is the concept of centration. This refers to the child's tendency to center his or her attention on the most obvious aspect of a situation and to ignore the other aspects.

Pre-operational children also think transductively, or from specific cases to specific cases (Flavell, 1963), and in the process they may come to believe that events which occur together are related and may even have caused each other.

At this stage of development children begin to play in earnest. Play is not a frivolous pastime, but is one of the main ways that children learn and develop. By re-enacting real life, children express emotions and act out situations that are worrying them and develop ways of dealing with them, It is thought that play could be seen as a form of stress management for children (Nagy, 1996).

Nagy (1948) and Anthony (1972) have both shown that the development of children's understanding of death changes according to the child's level of cognitive development and to their experiences. Younger children have difficulty in understanding that death is irreversible and may believe that the dead person has only departed temporarily. They may therefore have trouble accepting that if they die they cannot return to their parents. Nevertheless whilst young children may not fully comprehend death, they are frightened by it (Raphael, 1983). In general, children's concepts of death develop in a continuum, starting from infancy, when they have no understanding, to around the ages of eight or nine when there is a sophisticated understanding. Of interest to this study is the fact that some studies have shown that understanding can occur at early as five or six years of age. Children who have had close experiences with death, or have suffered life threatening illness may have a more advanced concept of death [1] (Bluebond-Langer, 1978; Landsdown & Benjamin, 1985).

3.1.3 School age children

During middle childhood, cognitive development makes a gradual transition to the concrete operational stage. The reasoning ability of concrete operational children is largely linked to their prior experiences since they are not good at imagining events or situations that they have never experienced.

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[1] This correlates with the author's own experience in caring for children with terminal cancer.

Concrete operational reasoning has elements of logic, providing that it is applied to situations that the child has experienced and not to the understanding of abstract concepts.

By the age of eight most children have well established concrete operational reasoning. A major development of concrete operational thinking is that the child has a reduction in egocentric thinking and an increasing ability to understand that their own views may not necessarily be those of others, which represents the beginning of the development of empathy. They may feel sympathy for someone who is distressed in similar circumstance to their own, and at the same time may have trouble empathising with someone who is in a situation that they have no experience with (Lucco, 1991).

During middle childhood play becomes more structured and cooperative as children develop the cognitive ability understand the need for rules. Cooperative play helps children learn social skills, negotiation and conflict resolution skills. It is also therapeutic in that it provides a means of dealing with fears and promoting feelings of control.

There is some variation in the age that children completely understand the concept of death, Landsdown and Benjamin (1985) found that 60% of five year olds and almost all nine year olds fully understood the concept of death. However, Bluebond-Langer (1978) found four year olds with a fully developed understanding of death, whilst Childers and Wimmer (1971) found ten year olds who had not.

3.1.4 Adolescence
During early adolescence a qualitative change in children's thinking ability occurs resulting in the stage of formal operations. This involves the ability to manipulate ideas or abstract concepts. The ability to reason deductively is a major cognitive achievement, because it enables adolescents to predict the outcome of events that they have not yet experienced. Adolescents have the ability to reason scientifically, or as Piaget termed it ' use hypothetico-deductive reasoning'. At this stage children can

formulate hypotheses and test them systematically, and can solve problems in a systematic way. In order to construct a personal ideology and develop their 'ethical system', adolescents turn their attention to questions regarding the nature of the world and attempt to grapple with religious, social and political issues.

Whilst adolescents are able to comprehend the full effects and implications of illness, they are however more likely to worry about the immediate rather than the long-term effects (Wilkinson, 1988). They have a full understanding of the universality and finality of death, but seem to believe that it will happen to others and will not happen to them (Krause, 1976). The adolescents' newly developed cognitive abilities allow them to utilise strategies for stress relief that were previously unavailable to them. Denial and intellectualisation are mechanisms often used, and there are also gender differences in the way that adolescents use coping strategies, with girls tending to utilise social supports more readily, and boys exhibiting more stoic behaviour in an attempt to keep others from knowing how bad things are (Frydenberg & Lewis, 1991).

3.2 Current theories of death and dying

Over the last forty years there have been a number of theoretical frameworks developed on the area of death and dying. For example, Glaser and Strauss (1965b), Kubler-Ross (1969), Pattison (1977), Corr (1992b) and Copp (1996) have all made important contributions. Earlier researchers, Glaser and Strauss (1965b) and Pattinson (1977), focused their attention on situations encountered in practice, particularly those encountered by patients who died in institutions. Their findings were based mostly on the perspectives of health care professionals.

Glaser and Strauss (1965a) used a sociological approach to analyse the context of awareness of dying in hospitals. They described a theory known as 'the context of awareness theory' that describes four contexts of awareness between health professionals and their patients. These contexts are:

(i) Closed awareness, which occurs when health professionals are aware of a patient's poor prognosis and make attempts to circumvent themselves having to disclose this information.

(ii) Suspicion awareness, in which the patient begins to suspect the seriousness of his or her condition and makes attempts to elicit confirmation of this from health professionals and carers. This situation places the patient, health professionals and family under immense psychological strain as each dances around the truth in an attempt to confront or avoid it.

(iii) Mutual pretence awareness, which may result from suspicion awareness if the patient, health professionals and family all become aware that the patient is going to die but pretend as if he or she will survive.

(iv) Open awareness, which is the collary to mutual pretence awareness in that all parties are aware of the patient's impending death and choose to acknowledge this in their words and actions towards each other.

Shortly after the context of awareness theory was published, Glaser and Strauss published another theory (Glaser & Strauss 1968), that proposed that there was a relationship between the phases of dying and several trajectories that accomplish death. These trajectories are described by Glaser and Strauss as:

- Certain death at a known time.
- Certain death at an unknown time.
- Uncertain death but at a known time when the certainty will be established.
- Uncertain death at an unknown time when the question will be resolved.

Glaser and Strauss proposed that the trajectory of an individual had two important elements, namely time and shape, which causes the specific death trajectory for an individual to vary in duration and form. The death process could be rapid or slow, it may plateau at some stage, or there may be short-term fluctuations in the patient's condition. These variations may lead to conflict and tension between patient, family and health professionals as an expected death trajectory changes.

The major strength of Glaser and Strauss' works lies in their grounding of their observations in practical experience. Because of this strength, they still remain relevant today, and influence the way that health professionals communicate with

dying patients. In addition, they provide valuable insight into the behaviour and response to the process of dying by patients, health professionals and families, and provide a sound base from which further research into the communication of 'bad news' to patients and families by health professionals can be launched.

Whilst Glaser and Strauss did not use paediatric patients in their research, their work is applicable to the paediatric setting. The awareness model in particular can be seen to operate as families often try desperately to keep the knowledge of impending death from their children who frequently have a firm suspicion, from watching the events that occur in other patients, as to what their likely fate will be. The difficulty with this model in paediatrics is that the family has a quite different relationship with both the paediatric patient and health professionals from that in the case of an adult patient. In many situations the need is for the situation to end in multiple awareness between the parties involved, and this is not accounted for in Glaser and Strauss' theory.

Kubler-Ross (1969) developed a theory that proposed a stage model of psychological response to dying which was based on the perspective of the dying individual. Her theory postulated five stages, termed denial, anger, bargaining, depression and acceptance. These described the process of psychological response by patients to the news that they were dying. According to Kubler-Ross, a person reacts to the shock of learning that they have an incurable illness by initially refusing to believe that this is the situation, thus denying it. This is followed by the second stage of anger towards the disease, institution, health care professionals, family and society, and the third stage of bargaining in which the patient may engage in making promises to God, for example, in an attempt to gain more time to live. The fourth stage of depression commences when it becomes clear to the person that he or she can no longer deny the progression of the disease, and the fifth stage of acceptance may occur if the patient has sufficient time and assistance to work through their grief and sense of loss. Kubler-Ross's concept of 'stages' stemmed from the Eriksonian concepts of childhood developmental theory detailed earlier. It provided an orderly sequence to the unfolding of the experience of dying, and for many health professionals provided their first academic exposure to the topic of death. In its structure it reduced anxiety in health care professionals by providing an ordered pathway for dying which filled a void in healthcare theory. Notwithstanding this contribution, her research has been

criticised from the methodological viewpoint in that she provided no data about her sample, did not define terms used, and that her findings have little internal validity.

Some researchers have further criticised Kubler-Ross's theory as being too prescriptive (Pattison, 1977; Rainey, 1988) and although she cautioned that a patient should not be pushed through the various stages, there is an implication in the theory that 'acceptance' is a valued destination. In providing a convenient orderly scientific approach to the subject of dying, Kubler-Ross's theory provided a screen that health professionals could hide behind when dealing with this difficult area.

Kubler-Ross used no paediatric subjects in her research, and given the multiplicity of responses that children of varying stages of cognitive development will exhibit coupled with the differing reactions between the paediatric patient, its family and health care professionals, it seems of extremely limited value in paediatrics.

Pattison (1977) drew on these earlier works and proposed the living-dying interval theory, in which he stated that we all project ahead an 'expected trajectory' for our lives. This trajectory will be changed when the individual confronts a crisis in their life such as the knowledge of impending death. Pattison defined the living-dying interval as time occurring between the knowledge of impending death and the point of death. This time could be divided up into three clinical phases: acute phase, chronic living-dying phase and terminal phase. He postulated that the first task of health professionals is to deal with the patient's reactions to the news of impending death, to ensure that the patient's life does not deteriorate into chaos, by focusing on reality issues and diluting such responses as described by Kubler-Ross. The second task is to respond to the ways that the patient adapts to the chronic phase and, finally, to enable the patient to move into the terminal phase.

Pattison's model, unlike previous theories, takes into account the need for integrated dying according to the speed of disease and reactions of the patient to their changing circumstances. Its strength is that it is capable of being related directly and meaningfully to everyday clinical experiences. It proposes a hypothesis that dying takes on an integrated or disintegrated form depending on the patients' response to the initial crisis phase. However a third form of dying that exhibits features of both

integrated and disintegrated dying occurring at different times, would be more appropriate to the paediatric setting, again as with previous theories the triangular nature of relationships between patient, family and health professionals adds a further dimension to the complexity of the situation.

Corr (1992b) re-examined the usefulness of previous models and drew upon knowledge gained by allied disciplines in the 1980's on coping and bereavement to look at how individuals cope with dying. During that period, bereavement studies focused on the area of grief work from a developmental perspective, taking the view that people needed to be involved in working on the 'tasks' of bereavement in order to successfully adjust to their loss. Whilst the concept of 'tasks' had been previously raised in Pattison's theory, Corr proposed a task-based approach to coping with dying and for those who care for the dying. His model utilised two central concepts, which he termed the notions of 'tasks' and 'coping with dying'. Corr elaborated on this by stating that persons who are dying have four areas to perform 'task work' in:

- Physical, relating to satisfying bodily needs and the alleviation of their physical symptoms.
- Psychological, to maximise their psychological well being, and richness of living.
- Social, sustaining their interpersonal relationships and addressing the social implications of their dying.
- Spiritual, identifying developing and reaffirming sources of spiritual energy, and by doing so foster hope.

Corr (1992b) was keen to point out that his task-based model operated from an individual's perspective and asserted:

> ...there is no single right way in which to cope with dying, although there may be better, worse and even unacceptable modes of coping from the standpoint of each of those involved (p. 83)

In regard to his second notion of 'coping with dying', Corr argued that coping takes on various forms and results in different outcomes depending on the differing points of view of various researchers. He further stated that:

> ...coping encompasses more than just reacting to or defending against the events and challenges of life, coping involves an awareness of events and challenges plus efforts to contend with them (p. 88)

The central underpinning idea of Corr's model is that the process of dying is not confined to the dying individual, but affects all those who are drawn into the individual's experience of his or her dying. Corr further argued that to be of any use a theory should contribute to improved understanding, empowerment, participation and guidance for carers to cope with dying. Although Corr used the notion of 'tasks' as central to his theory, it is clear that the concept of tasks in this context suggests active participation by the dying individual and those involved in his or her care.

Criticism of Corr's model has been directed toward the need to identify and examine in greater detail the various tasks and sub-tasks related to coping and the relationship between these tasks, death and everyday life. From the viewpoint of paediatrics it is clear that Corr's theory is a major step forward towards understanding how the patient, family and health care professionals can interact, in various ways, to work through the issues that confront them when faced with the death of a child. It presents a multi-dimensional framework including the physical, psychological, social and spiritual aspects of dying and the relationships between dying individuals and their carers, which by implication will extend beyond the death of the child into bereavement.

More recently Copp (1996; 1997) has attempted to formulate a new theory that addresses some of the deficiencies found in earlier contributions. Copp undertook a study from a nursing perspective, arguing that although it is acknowledged that nurses provide continuity of care that includes caring for dying individuals, the nature of the nurse-patient and patient-nurse relationships remains largely unexplored in the setting of caring for dying patients. The primary focus of her study was on the patients' management of, and experiences in, confronting their impending death, and their nurses' experiences in caring for individuals as they progressed through the dying process rather than their response to this imminent event. Copp argued that patients and nurses continually engage in a dialogue which takes many forms, from face-to-face contacts, to manoeuvring behind the scenes. The interactions that occur in this dialogue all come under the umbrella of 'caring'. Acts of protecting and controlling, watching and waiting, holding on and letting go that occur as part of these relationships have been identified and provide key elements in understanding the complexities that are acted out between the participants in the process of dying.

During interviews with patients and their nurses, Copp frequently found reference to the concept of separation of 'body' from 'self'. In particular, nurses made direct reference to seeing the 'body' as a separate entity from the 'self' when making attempts to gauge a patient's readiness to die. Copp's theory highlighted the notion of separating body and self as a paradigm for understanding a person's readiness and acceptance of their death. However, her study was designed to study the experiences of adult patients with cancer who were dying in the hospice setting and had prior knowledge of their disease prognosis. This clearly limits the applicability of the concepts into paediatrics because children, as stated earlier, often do not know that they are dying, and have differing understandings of what this means. In addition in the paediatric sphere, death from malignancies account for only about a third of all deaths with many paediatric patients dying from long chronic degenerative illnesses.

3.3 Death in the paediatric setting

In 1971 Waechter convincingly illustrated that dying children need to talk to adults about what is happening to them. She measured the anxiety scores of hospitalised children, some of whom had terminal illnesses and some who had chronic illness but were not of a terminal nature. The anxiety scores of those patients with a terminal illness were double that of the patients with a non-fatal disease. When Waechter used pictures to elicit stories from the children, it was clear from the stories of the group of children with a terminal illness, that even though they had not been made aware of their impending death they were all somehow aware of their poor prognosis.The stories from those children in this group who had not had the opportunity to talk to adults about their fears and anxieties, were far darker in content and imbued with feelings of isolation, alienation and death (Waechter, 1971). The fear of dying alone and unsupported is far worse than the fear of dying in the care of one's family and caring health professionals. Whilst in the past, it has been argued that there is not much that can be done to relieve the anxiety of a child with a fatal illness, such feelings as those just described may unnecessarily disturb the child and family's last few months of life. The conclusion from Waechter's work is clear; children must be given honest and sensitive communication about their illness and prognosis from the time of diagnosis. To accomplish this, it is critical that the adults in this dialogue understand the meaning of death to the child. Effective communication with dying

children must not only be honest, it must be consistent with the child's cognitive ability to understand the concept.

A further problem is that dying children and their siblings need maximum support from their parents at a time when they, the parents, may be least able to give it due to their own grieving processes. When parents and health professionals become aware of their child's poor prognosis, they almost inevitably begin their 'grief tasks' before the child dies, this phenomena is known as 'anticipatory grief'. Knowing in advance, however, does not necessarily mean that all parents or health professionals will exhibit anticipatory grief. Parents may experience other emotional responses such as denial or anger that may inhibit this developing, and health professionals may feel a sense of failure and guilt.

Siblings also need honest and clear communication at an appropriate cognitive level to understand what is happening. There is clear evidence that post-death adjustment is better in children who are kept fully informed and participate in the care of their dying sibling (Jurk *et al.* 1981; Pettle & Landsdown, 1986).

The 'tasks of dying' for the individuals involved, do not end with the death of the child. They continue well into the grief process, where, for example, fathers may grieve differently than mothers, and their grief may not be acknowledged by the other partner. Both may grieve differently to siblings and extended family members who may have been involved in the dying process, thus allowing misunderstandings and tensions to arise between family members who grieve in different ways.

3.4 Conclusion

There has been progress in the area of finding a theoretical framework to describe the practice and reactions of people involved in the dying process. These earlier works have provided a basis for a re-examination of health care professionals' attitudes towards the care of dying patients and their families. Although the approaches undertaken by the authors vary, there seems to be a gradual shift towards a more inclusive and interactive framework to reflect the multifaceted nature of death and dying and its effect on the patient, family and health care professionals. This is especially important in paediatrics where the interplay between families, their

children and their health professionals is modified by the developmental stage of the child concerned.

This research will utilise Corr's theory on a task-based approach to coping with dying by patients, their families and the health professionals who care for them. Corr's theory presents a multi-dimensional framework, in that it includes the physical, psychological, social and spiritual aspects of dying together with the relationships between dying individuals, their families and their caring health professionals within these aspects. This, by implication, will extend beyond the death of the child into bereavement. However, for this study, Corr's theory needs to be integrated with Piaget's theories of cognitive development, which illustrate the differing emotional requirements of paediatric patients at different stages of development. This of course will impact on the number and type of 'tasks' that are required of families and health professionals in caring for them.

The next chapter will deal with methodological issues, the rationale for the particular approach used, and details of the environment and sample. Following this, specific details of the needs analyses of both staff and families, and issues around the credibility consistency and applicability will be explored. Finally the ethical considerations of undertaking this research will be detailed.

Chapter 4 Methodology

4.0 Introduction

This chapter will provide detail about the research approaches employed in the study, techniques used to enlist subjects, methods of data collection and the analysis techniques used in this project. As stated earlier, this research study was approved by the ethics committees of both Victoria University and Royal Children's Hospital.

4.1 Background

Interpretive nursing research methods seek, through observations, interviews, literature and personal records, to describe, document and theorise about phenomena as and when they occur, by capturing peoples' meanings, definitions, and descriptions of events. Over the last 30 or so years, nursing research has embraced a plethora of views on the world. The viewpoints and theories of Agan (1987), Parse (1987), Meleis and Schultz (1988), and Newman (1992) among others have influenced the way nursing goes about acquiring and assessing knowledge about itself and its interaction with others. These methods focus on individuals' understanding of the meanings that they attach to events in their environment.

The trend towards qualitative research methodologies in nursing is a response to the perceived limitations in quantitative methodologies. Although these quantitative methods can clearly describe situations and events where there is some evidence of causality, they can leave nurses in danger of missing a wealth of rich data of a 'softer' nature that allows an interpretive understanding of the phenomena under study. Nursing, however, should not exclude quantitative methods of research and blindly subscribe to qualitative methodologies. The classification of all qualitative research as inductive and all quantitative research as deductive is too extreme, as both methodologies utilise inductive and deductive reasoning in their analytical procedures (Minichiello, Aroni, Timewell & Alexander, 1995). It is important to realise that quantitative methodology extends beyond in-depth interviewing and that sometimes a multi-method approach utilising techniques

such as survey questionnaires and content analysis of the literature, yields different dimensions and insights into the phenomena being studied. This integration of a multi method approach is known as triangulation (Denzin, 1989). Such a multi-method approach was used in this study, to not only identify themes around the provision of palliative care at the Royal Children's Hospital, but to highlight the extent to which those themes impacted on the practice of the hospital staff.

4.2 Death Audit

From data supplied by the RCH medical records department in 2000, the medical records of all RCH patients who had died in the twelve months from June 1998 – June 1999 were examined to determine:

- age at death.
- diagnosis and cause of death.
- place of death (home, hospital, other).
- medical unit and consultant.

This death audit was an essential step in this study because it allowed the researcher to attempt an identification of those areas of clinical care that had a higher number of deaths occur, and consequently to map the demographic data of those children who had died. The purpose of this mapping was to provide details of the three categories involved in the development of the theoretical sample that was used to select staff respondents (4.4.1) and, separately, respondents who fitted the three categories in the theoretical sampling profile of bereaved families (4.4.2).

4.3 Analytic induction

Analytical induction is a concept that underlies qualitative research. This approach can aid the researcher to build, test and modify propositions whilst collecting the data. Analytical induction allows the research question to evolve in response to clinical insights that emerge from concurrent data collection and analysis. In analytic induction, rather than merely collecting data to verify an existing hypothesis, understanding is allowed to emerge from the chosen area of study (Glaser & Strauss, 1967). The purpose of this approach is to build an understanding that throws light on the phenomena under

examination. In consequence, the data is continually analysed and compared to look for similarities between significant aspects. These similarities are then clustered together to deliver themes. Themes can then be developed through: selective literature sampling and comparison with existing data; further collection of data; and development of levels of coding, into a theory that describes the core variable (Strauss & Corbin, 1990). Sampling should be guided by the need for contrasts that are needed to clarify the analysis and allow for the categories that are emerging to be saturated, that is, no new information or insights into that particular category can be gained (Glaser & Strauss, 1967).

4.3.1 Rationale for using the analytic induction approach

Nursing is a practice-based profession which has at its heart 'process', and the mere description of facts is often not enough to expand nursing knowledge, because this does not give any insight into the underlying processes. By utilising the analytic induction approach, nurses can identify and explain the generalities that will form theories, without failing to appreciate that they will be applied in the contexts of individual patients and health professionals and the interactions between them.

The analytic induction approach develops theories based on the study of human conduct and the concepts that impinge on it, and provides a means of conceptualising interactions between individuals and groups in response to crisis and change (Strauss & Corbin, 1990). In this approach, reality can be considered to be fluid, since it is in a constant state of recreation and modification. The analytic induction approach therefore is a process rather than a product-oriented approach, in that it embraces multiple realities, and rather than produce a description based on the beliefs and values of the researcher, provides an eclectic view of the truth in any situation by allowing for change over time by encouraging the participants to tell the story as they see it. It allows theory to be developed from practice and enhances understanding of the world of nursing and its interaction with patients.

As previously noted, Corr (1992b) postulated a theory of a 'task' based approach to coping with dying and providing care for the dying individual. The central underpinnings

of Corr's model are that the process of dying is not confined to the individual, but affects all who are drawn into the individual's experience of his or her dying, and that the concept of 'tasks' in this context suggests active participation by the dying individual and those involved in caring for him or her. However Corr's model has been criticised for not identifying those 'tasks' related to the dying process.

The use, in this investigation, of analytic induction as a process for illuminating paediatric palliative care is entirely congruent with Corr's theory. It allows an examination of the process of providing paediatric palliative care from the perspectives of all participants, and permits the construction of a multi-dimensional viewpoint from which to view the physical, psychological, social and spiritual aspects of paediatric palliative care and the needs of all involved within these aspects. From this multi-dimensional viewpoint can then be constructed a model of palliative care that identifies and describes the various 'tasks' that need be performed by participants in the paediatric palliative care process and best allows them to meet their needs, thus answering the earlier criticism of Corr's model.

4.4 Sample selection

The reason for selecting a sample is to produce either a representation of a chosen population, or a group of respondents that may 'illuminate a situation, get insight, or collect information about a particular event' (Wadsworth, 1984, p.14). Because the purpose of this study was to analyse and describe paediatric palliative care, it was necessary to let the developing insights 'guide' the data collection, within the context of existing theories previously described in chapter 3. Whilst there are several approaches that the researcher can utilize, for the purpose of this study it was felt that senior medical and nursing staff and allied health professionals from the four units that had been identified in the death audit as having significant numbers of children who had died in the previous year, would provide a rich source of data. This approach suggested that the project should engage in theoretical sampling. Burgess (1984, p. 56), argues that 'theoretical sampling...involves researchers in observing groups with a view to extending, modifying, developing and verifying theory'. The process of theoretical

sampling is a flexible one, that allows the researcher to select respondents in response to the uncovering of relevant themes, categories and issues that are critical to the study (Minichiello *et al.* 1995). The initial respondents were selected on the basis of their specific perspectives from which they could contribute to an understanding of the process of providing paediatric palliative care. However as the research data uncovered new and relevant themes it became necessary to include further respondents in response to this new and emerging data. This approach gives the researcher the flexibility to fully explore relevant themes as they emerge. Sampling therefore was cumulative, with respondents chosen initially in response to categories that were derived prior to the research, then augmented by further respondents who fitted typologies that emerged through the study. In summary, the final sample had therefore two types of respondents:

Type 1. Respondents units and situations that have been purposefully selected because the literature and preliminary research have identified them as potentially having relevant input into the study of paediatric palliative care.

Type 2. Respondents that have been included in the sample as a result of themes that have emerged during the data collection. Examples of such respondents are:

(i) An RCH organ transplant co-ordinator; a registered nurse, who works closely with newly bereaved families to identify and co-ordinate the supply of transplant organs to pediatric patients, and also works closely with the families of children who are on organ-transplant waiting lists. This latter group of patients, their families and their health-professional care providers have been identified, in this study, as having extreme difficulty accepting the notion of concurrent active and palliative care.

(ii) Nursing and medical staff in the emergency department; these staff members are often required to care for terminal patients with an acute deterioration when they present unexpectedly to the RCH. They often are unaware of previous treatment decisions made between the family and the acute treating team, and in the emergency situation have limited time to ascertain the wishes of, and discuss an appropriate treatment plan with, the child's family.

(iii) Patient services assistants (PSA's); who are often engaged in closely providing hospitality services to patients with terminal disease and their families. These staff members almost invariably become involved in the palliative care process, in an informal

way by, by providing conversation and support, in the normal execution of their workplace duties, whilst both the child and the family are in the hospital setting as an inpatient or outpatient. The author feels that the identification of this group of staff constitutes and important finding as they have been not been previously described in the literature as being intimately involved in the dying process.

The theoretical sampling method is suited to this research as the diversity of hospital staff makes obtaining a truly representative sample from this heterogeneous population extremely difficult. Each medical unit, for example, deals with children from a particular medical discipline such as oncology, and comprises staff from medical, nursing, and various allied health disciplines, each of whom has a different degree of experience and seniority. Furthermore there are staff members who hold appointments across disciplines such as pastoral care workers, social workers and administrative staff at various levels. In order to incorporate responses from all aspects of the hospital, a stratified sample of enormous size would be needed, and even so it is doubtful whether it would be truly representative.

Within the families group, similar difficulties present themselves when selecting a sample. Each group as described by Goldman *et al.* (1990) contains patients suffering from disorders from differing medical specialties, and comprises families from rural or urban communities, single parent, split-parent, or conventional families and families who have had a previous experience with childhood death or more than a single child affected. These differences along with the varying length of the individual child's illness and differing cultural backgrounds make obtaining a truly representative group impractical.

4.4.1 Staff sample

As previously stated, it was felt that hospital staff from the four units identified in the death audit as having the most involvement with dying children, would provide a rich source of data. This project was widely publicised within the hospital by posters, staff news bulletins and word of mouth.

The theoretical sample was built up from the four categories outlined here:

(i) Medical unit

This study is concerned with the interactions involved around the process of caring for dying children and their families. Waechter has reported that as the death of a patient became imminent, the number and length of contacts made by nursing staff engaged in providing their care decreased (Waechter, 1971). As a consequence, it was felt that investigation of those nursing staff members who worked in those units (Oncology, Neurology, Cardiac and Neonatal) that had been identified as having a larger number of deaths might provide valuable insights into the nursing process of delivering care to dying children and their families.

(ii) Discipline

This category was chosen because the literature indicates that health professionals have different relationships with their patients and, by implication, their families. Whilst the literature shows that the medical profession clearly drives decision making in acute medicine, it has been suggested that nursing staff play a bigger role in the decision making around some of the issues of providing care to dying individuals. The literature also suggests that the involvement of other health care professionals may have a positive impact on the quality of care provided to terminal patients. However, Wheeler *et al.* (1985), Lattanzi (1985), Papadatou (1991) and Potter(1980) suggest that stress in staff members caring for dying children is likely to be unacceptably high and may affect their ability to provide care in a sensitive and professional manner. Respondents were recruited from professional groups in three disciplines; Medical, Nursing and Allied Health.

(iii) Level of responsibility

This category was chosen because the literature shows that the experience level of staff working with dying children is directly associated with the quality of care. The literature suggests that palliative care staff require greater sensitivity to caring and greater maturity (Farrow, 1981) and have specialised paediatric and palliative care experience (Wilson, 1985) before they can offer meaningful support to dying children and their families. Eakes (1984), suggests that inexperienced staff contribute to increased stress levels within those units caring for dying children. Consideration was given to the possibility that staff who had little or no experience in dealing with severely ill children and their

families found caring for dying children more difficult. This category was chosen as it was felt that those staff with previous experience with severely ill children would provide insight into the problems associated with their care. Respondents from within the previously described professional groups were recruited with both senior and Junior levels of responsibility.

Table 2. Dimensions of theoretical sampling categories representing Type 1 staff respondents.

Unit	Oncology			Neonatal			Cardiac			Neurology		
Discipline	Medical	Nursing	Allied Health	Medical	Nursing	Allied Health	Medical	Nursing	Allied Health	Medical	Nursing	Allied Health
Rank S= Senior J= Junior	S J	S J	S J	S J	S J	S J	S J	S J	S J	S J	S J	S J

4.4.1.1 Data acquisition tools

The following tools were utilised in the collection of information from staff at the RCH:

(i) Semi-structured interviews with individual staff. These were carried out with selected individual staff, who had been identified by the death audit, and in the literature, as having a potentially high degree of involvement with dying patients. The staff members who were invited to participate in these interviews fitted the categories in the theoretical sample and were therefore category Type 1 respondents. A description of the questions asked in the interviews is given below and detailed in Appendix 3.

(ii) Focus groups. Groups of individuals from units or departments containing both Type 1 & Type 2 respondents, usually, but not always, from a single discipline, met with the researcher to discuss issues around caring for patients with a terminal illness. In addition, staff members who felt uncomfortable in the focus group situation, or who wanted to explore sensitive issues, were offered individual interviews at the conclusion of

their focus group. This allowed further information to be collected on a number of themes as well as facilitating exploration of issues raised by individual respondents. All interviews were conducted by the researcher to facilitate exploration of themes identified in the focus groups. Whilst all interviews and focus groups were guided by the same guideline set of questions described below and detailed in Appendix 3, issues raised by participants that were outside the interview guide were also explored within the focus group or interview.

In the semi structured interviews and the focus groups carried out with selected staff members the following 12 areas were explored:

1. How many children in your care have required palliative care in the last 12 months?
2. How was this information communicated to the child and their family?
3. What services from within the hospital were engaged in the palliative care of your patients?
4. Were any community services involved in the care of these patients?
5. In your experience, have all members of your team shared similar views regarding the care of dying children?
6. Would more patients be suitable for care at home if supports were available.
7. How are family wishes regarding the death of their child currently communicated
8. What hospital supports are available to staff who experience distress during or after the terminal phase of a child's illness?
9. What do you perceive are the barriers to the provision of effective palliative care at the RCH?
10. Do you have an approach to the follow-up of bereaved families?
11. Would it help you to have access to expertise in paediatric palliative care?
12. Have you, or your unit, undertaken any research in this area?

These questions were designed to probe the respondent's current experience of involvement with patients requiring palliative care at the RCH, and given the range of perspectives obtained from the theoretical sampling procedure, a useful broad picture can be built. By targeting specific cases that the individual respondents had been involved with, it was hoped to sharpen their focus to illuminate the specifics of what they believed to be their definition of palliative care and their criteria for applying this definition to their patients. Respondents were asked questions about the development and communication of a management plan for their patients and families. The respondents' knowledge of and utilisation of other supports for their patients and families is also explored as is an assessment of how they thought those other services were of benefit, or otherwise, to the patients and families, and how they integrated into any overall

management plan. The respondents' ideas and practice of bereavement care were also elicited. Respondents were also asked specific questions, designed for some degree of introspectivity, around the improvement of their services both from an individual viewpoint as well as from an institutional viewpoint

(iii) Survey. In an attempt to validate the focus group/interview guide, an early thematic analysis was carried out after completion of data collection for the first 20 participants, which included staff from medical and nursing backgrounds, to identify common themes. A brief survey was developed and was circulated to the nursing and medical groups in an effort to gain a quantitative understanding (Minichiello *et al.* 1995) of the more commonly raised issues. The specific questions of this survey are given in the section below and detailed in Appendix 4. In this survey, participants were asked to rate on an eleven point scale from 'poor' to 'excellent', their response to the following nine questions:

1. The current communication and documentation procedures regarding the palliative care of patients are;
2. The interface between the RCH and community agencies as regards palliative care is;
3. My personal knowledge of the services available for palliative care patients is;
4. Coordination of services for patients with palliative care needs within the RCH is;
5. My knowledge of bereavement care and services available to bereaved families is;
6. Utilisation of nursing and allied health staff in discussions with families is;
7. Financial assistance and practical supports (eg. Respite) for palliative care patients is;
8. Facilities for the care of children and their families at the time of death are;
9. Ethical and legal support for difficult decision-making and conflict resolution is;

Each of the nine questions represents a theme that had emerged from the first 20 interviews. The data from this survey is represented graphically in the relevant sections of chapter 5. Analysis of this data was limited to percentages of respondents.

4.4.2 Family sample

The period 1998-1999 was chosen for this study because, the time elapsed between the death of the child and this study may have allowed time for the families to come to some sort of acceptance of their child's death. In addition, there was time available for families to view the terminal phase of their child's illness, and the care delivered during that phase, with some degree of objectivity. By providing such a time buffer it was hoped to reduce the stress levels on the families who became involved in this study. Using data from the death audit of children who were treated at the Royal Children's Hospital, Melbourne and who died during 1998 –1999 a group of families was selected using theoretical sampling as detailed by Minichiello *et al.* (1995), on the basis of the following selection criteria:

(1) Goldman group

Goldman *et al.* (1990) have described four broad groups (1, 11, 111, 1V) of children who require palliative care (Section 1.1). However staff respondents at the RCH reported that there was difficulty in defining palliative care, and also in establishing that individual patients were indeed needing palliative care. This criteria was chosen to ascertain whether patients and families in all the groups described by Goldman *et al.* had the same problems in the definition and application of this definition to them as requiring palliative care.

(2) Place of death (either home or hospital).

This category was chosen to try and elucidate whether the choice of caring for the child at home had any effect on the difficulties experienced by families in obtaining appropriate palliative care and to identify those difficulties.

(3) Interaction with community palliative care programme (yes or no).

This category was chosen to ascertain if involvement with a community based palliative care programme altered the experience of the palliative care process from the families' perspective, and also to ascertain if the timing of a referral to, or connection with, a community based palliative care programme had an effect on the families' experiences.

Table 3. Dimensions of theoretical sampling catergories representing Parent/ Family respondents

Goldman Group	1		11		111		1V	
Place of Death	Home	Hospital	Home	Hospital	Home	Hospital	Home	Hospital
Involvement with community palliative care	Y N		Y N		Y N		Y N	

The families were interviewed using in-depth unstructured interviews, asking them to talk about their child's death. In essence, this strategy allowed families to provide their story, using the recursive model as described by Minichiello *et al.* (1995), during a

conversational interaction between the interviewer and family. This approach meant that the interviewer could direct the conversation and to explore specific aspects of the respondent's story such as; access to medical, nursing and social support, access to relevant information and positive or negative aspects of their care during the terminal phase of their child's illness. At the same time this approach still allowed the introduction of material that was specific to that particular family's experience. Family members were, wherever practical, interviewed together, so that the differing views of members, on the same subject or aspect, could be explored.

An initial letter of introduction was sent to the families (Appendix 1). This was followed by a telephone call two weeks later to ascertain their willingness to participate. All interviews were conducted by the same interviewer (author), and the interviews were tape-recorded with prior consent of the respondents.

The qualitative research design, using the analytical induction approach, allowed the construction of categories from the stories told by staff and families about their experiences during the terminal care of dying children. Analysis was done concurrently with the interviews, each interview being transcribed, and the transcription checked by the author against the original tape for accuracy. Each transcription and tape were then read and heard together several times. Phrases that were seen to be significant were identified, a description of both their content and the way that the subject used them prepared, and finally the responses were coded. Analysis and coding of each interview was done before the next interview was commenced, allowing new data from ongoing interviews to be added to that already collected. This process ensured that the data was constantly reviewed and compared. Coded data was grouped into themes that reflected the whole of the data collected. As an example, comments around perceptions of treatment decisions, or staff members differing perceptions of medical interventions, were grouped into a theme, whilst other comments around differing information given to patients, families and hospital staff by various members of the caring team were grouped into another theme. These themes were then brought together into a category of 'Conflict'. New data from interviews was analysed and added to existent data for

comparison and review. In this way, several major themes were identified. All the data was then reviewed and also compared to the themes that had emerged from the literature review around staff and parental perceptions of the issues involved with providing paediatric palliative care.

The point of completion of staff and parent interviews occurred when the saturation level was reached, that is when no new concepts were identified that were not situation specific (Glaser & Strauss, 1967; Glaser, 1972).

4.5 Research rigour

Accurate representation of subjects' experiences around the phenomena under study is the goal of rigour in qualitative research. Several authors have described the criteria used to determine the methodological rigour of a qualitative inquiry, these are: truth value or credibility, applicability, consistency and neutrality (Sandelowski, 1986; 1993; Munhall, 1994; Guba & Lincoln, 1981). Issues of rigour have been assessed by the following criteria during the course of this research:

4.5.1 Credibility

Credibility centres around activities that increase the probability that credible findings will be the result of the analysis. As Munhall says 'whether a description of an experience is credible to the person with experience is a primary consideration' (Munhall & Oiler-Boyd, 1993, p.155). He then later elaborates, 'when a credible description is read, and the reader can identify with the description, the reader nods in agreement and recognition, the *'phenomenological nod'* [italics added] occurs' (Munhall, 1994).

To confirm the findings of this study, the meanings and analysis from the total interviews were relayed back to the participants in the form of an exhaustive report. Feedback was then provided back to the researcher from the participants who validated that they were, in fact, accurately represented by the findings. However it is important to acknowledge that not all aspects of a completed description will be true for all subject participants, as

the description will represent different contexts and a wide variation in attached meanings (Munhall, 1994).

4.5.2 Applicability

Applicability refers to the findings of the study having meaning to others in similar situations. Its evaluation is determined by the 'fit' of the findings into other contexts that are outside the situation of the study (Munhall, 1994). To assess the applicability of the findings in this study, they were formally presented to practitioners of palliative care, in the medical, nursing and allied health fields, from interstate and international paediatric hospitals at conferences and seminars such as the 6*th* *Australian Palliative Care Conference, Hobart, September, 2001* and the 7*th* *Biennial International Pediatric and Child Health Conference, Sydney, May, 2002*. Participants at these conferences confirmed, during discussion and question times, that they could relate well to the findings and in fact recognised much of their own experience in them.

4.5.3 Consistency

Consistency in qualitative research is achieved when a record of research activities or 'audit trail' allows other researchers to easily follow the research process undertaken (Streubert & Carpenter, 1995). The aim of the audit trail is to illustrate the processes and evidence that lead the researcher to his conclusions. By doing this, the researcher allows for the replication of the study with similar conclusions by other researchers (Sandelowski, 1986).

To this end, the researcher has, in the written presentation of the study, clearly defined each phase of the research process, the techniques used to ascertain credibility and applicability of the data findings. The use of quotes from the participants throughout the findings further enhances the auditability of the study.

4.5.4 Neutrality

In qualitative research the notion of neutrality refers to the freedom from bias in the conduct and analysis of the research (Sandelowski, 1986). Munhall (1994) acknowledges

that a degree of subjectivity is inevitable in any description of reality and sometimes is viewed as necessary and desirable suggesting:

> This inevitability is not stated with resignation, but with the idea that subjectivity expands and enriches the authenticity of perceptions and understandings of phenomena (p.14).

Sandelowski suggests that neutrality is achieved when the other parameters of credibility, applicability and consistency are established (Sandelowski, 1986). The author's descriptions of the measures utilised to establish the other parameters ensure the neutrality of the research.

The measures described above and undertaken by the author, have enabled the material presented in this thesis to be scrutinised by practitioners and scholars in the field of palliative care, and peak bodies representing parent interest groups. This process, together with actively seeking their feedback and comments on the methodology and findings, has ensured that the question of rigour in this research has been fully addressed.

4.6 Ethical considerations

Much consideration to the participants' interests and their well-being was given during the conduct of this research, particularly to that of the family group of subjects, with ethical issues of informed consent and confidentiality being carefully addressed.

Participants were provided with both verbal and written information which outlined the voluntary nature of participation in the study (Appendix 1; Appendix 2), the purpose and aims of the study, method of collection of data, confidentiality and the use to which the findings would be put. Each parent respondent provided written consent, to the researcher, and had an understanding that they could withdraw from the study at any time and for any reason. Hospital staff members were fully informed of the study by a publicity campaign throughout the hospital. Consent by staff participants was implied by their attendance at interviews and focus sessions.

All data for the study have been maintained as confidential. It was ensured that each family or staff subject could only be identified by the researcher, by the substitution of family names with fictitious ones and the identification of the children by letters of the alphabet. The list of pseudonyms and corresponding names has been kept by the researcher in another location, physically apart from the data transcripts and tapes. Data from the staff interviews and focus groups were distilled into disciplines, and the names of staff respondents who participated in interviews and focus groups were not transcribed during the interview process. Only the professional discipline of respondents has been mentioned, and all identifying references disclosed during the interview process have not been divulged during any dissemination of research findings.

In accordance with ethics procedures, all tapes, transcripts, computer discs and related documentation used in the study have been kept securely under lock and key by the researcher at the Royal Children's Hospital. On completion of this project, the research material will continue to be kept under the same conditions for a further period of five years, then destroyed.

It was planned that participants who suffered a painful or emotive experience that was traumatic to them, would receive an offer to immediately cease the interview, and undergo counselling. In the first instance this was to be provided by a skilled social worker and grief counsellor at the Royal Children's Hospital, with a subsequent referral on to a community-based, suitably qualified professional counsellor if needed. To this end, agreement from the Social Work department at the RCH, to provide this backup service, was sought and obtained prior to the commencement of interviews. Whilst some distressing situations did occur to respondents during the interview process, no situations occurred where the interview was either ceased or participants needed referral to counselling. All participants were made aware that comments on the conduct of the researcher could be made directly to the ethics committees of either Victoria University or Royal Children's Hospital. Contact details for these were on the copy of the consent form held by the parents interviewed.

The next chapter will discuss the findings of the research from both staff and family interviews together with quantitative data obtained from the survey sent to the nursing and medical groups.

Chapter 5 Findings

5.0 Introduction

Results from the death audit, staff interviews, focus groups, survey questionnaire and family interviews are detailed in this section. Themes elicited from the staff interviews and focus groups are enhanced by the inclusion of quantitative data from the staff questionnaire. Where quotes are used, they are representative of similar comments made by many staff; however they are attributed to their source only.

5.1 Death audit

In the twelve months from June 1998, the RCH was notified of the deaths of 225 patients, 175 of whom died in the RCH and 50 in settings outside the hospital.

Table 3: Diagnosis and place of deaths

Diagnosis	Inpatient	Outpatient	Goldman (1990) Group
Cystic fibrosis	6	2	II
Malignancy	24	16	I
Cardiac anomalies	33	6	I, II, IV
Static/progressive encephalopathy	8	13	III
Muscular dystrophy	3	3	III
Metabolic	4	1	I, II, III
Congenital anomalies	25	3	I, II, IV
Other	16	4	I, II, III, IV
Sub Total	119	48	N/A
Acute deaths[2]	56	2	N/A
Total	175	50	N/A

Patients of the Royal Children's Hospital (June 1998-May 1999) n = 225 [3]

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[2] Sepsis, Trauma, Asthma, Sudden Infant Death Syndrome, Collapse, Respiratory obstruction, Hyaline membrane disease, Hydrops fetalis, Haemolytic uraemic syndrome.

[3] This statistic is supported by the Victorian Consultative Council on Obstetric and Pediatric Mortality and Morbidity Report (1999), which reports 240 childhood deaths for the previous year.

From the data, it can be seen that 119 inpatients and 48 outpatients, and their families, potentially required palliative care pre-death. Within the RCH, these medical units had the greatest occurrence of deaths; Oncology (40), Cardiac (39), Neonatal (28) and Neurology (27). Together they account for 80.2% of deaths of patients who potentially typically require palliative care pre-death. Patients belonging to all of the groups described by Goldman (1990) are represented, with several units having patients in more than one group. Deaths occurring outside the RCH accounted for 24.5% of the deaths of patients who typically potentially require palliative care pre-death. From the data available, it was not possible to ascertain in what setting these patients died (i.e. home, hospice, or regional/ interstate hospital).
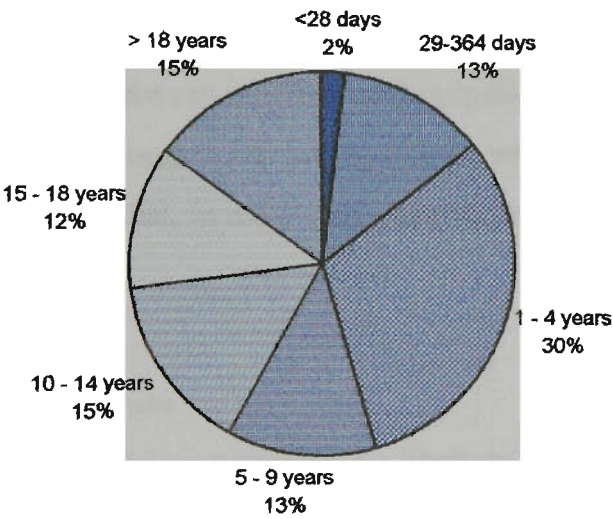
Figure 2. Outpatient deaths by age: June 1998- May 1999. n=48
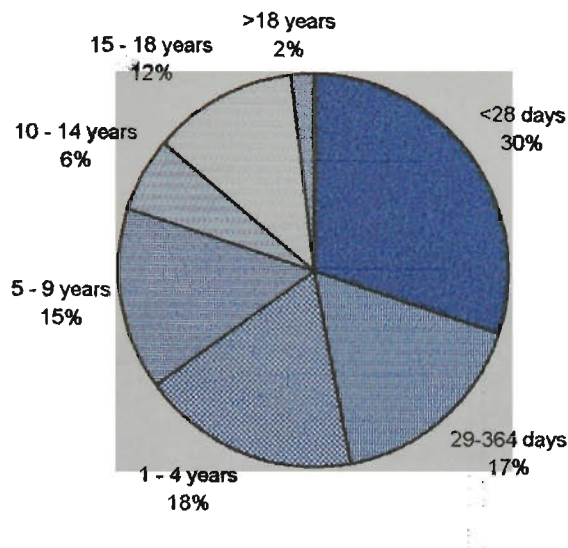
Figure 3. Inpatient deaths by age: June 1998- May 1999. n=119

As can be seen in Figures 2 and 3, deaths occurred in all age groups. However the distribution varied markedly between inpatient and outpatient settings. This most likely represents the fact that most neonates and young infants will be inpatients, and that the RCH has an admission policy that, in most cases, precludes admission to patients older than 18 yrs.

5.2 Staff interview response rate

From the death audit, 120 Type 1 respondents, i.e likely to have a high degree of involvement with dying children and their families, were identified in the Oncology, Cardiac, Neonatal and Neurology units. Whilst these were mainly in the medical and nursing disciplines, staff members in physiotherapy, occupational therapy, social work and pastoral care disciplines were also identified as Type 1 respondents. These staff members were targeted for inclusion in the study as it was felt that they represented the current practice of palliative care at the RCH.

A final total of 166 members of staff, representing a wide range of professional groups and specialties, were interviewed or participated in focus groups (Figure 4). This number includes the 120 Type 1 respondents identified from the death audit and literature review,

and 46 Type 2 respondents who were identified during the course of interviewing and conducting focus groups.
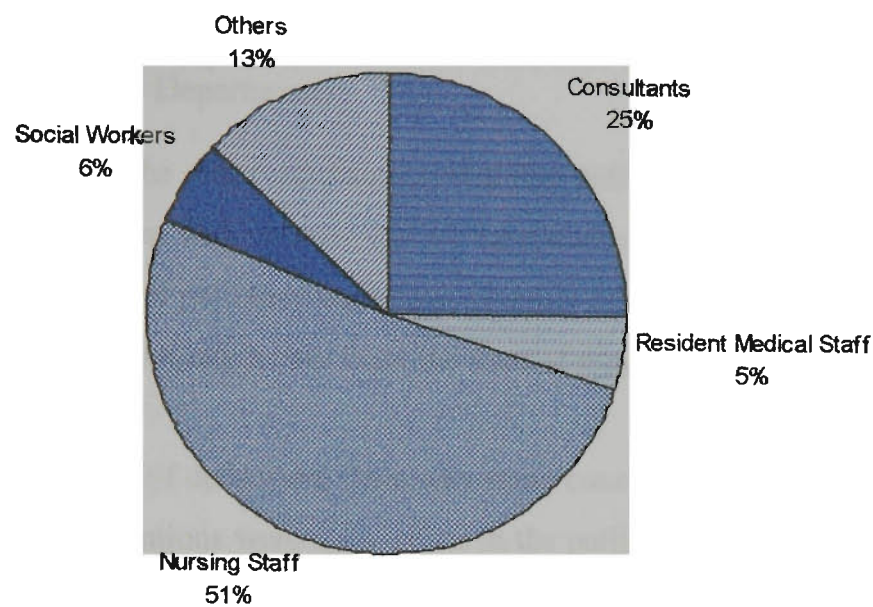
Figure 4. Respondents interviewed, by professional groups. n=166

5.3 Themes from RCH staff

As expected, a number of themes emerged from the staff interviews and focus groups. These 14 themes are detailed in the subsequent sections, and have been enhanced by the inclusion of quantitative data from the survey questionnaire, that was sent to the 120 Type 1 respondents with 75 replies (62.5%) from 29 consultants, 26 nursing staff, the remainder were unidentified.

5.3.1 Concerns regarding the definition of Palliative Care, and appropriate medical interventions

Many respondents, from all disciplines, were uncertain of the meaning of the term 'palliative care'. For example one respondent suggested that:

> I think there are a lot of people who find it [palliative care] difficult to identify and then to liaise with the community about it (Senior consultant, Neurology Unit).

There was awareness of the discrepancy between the literal meaning of the word 'palliate' and the fact that in RCH practice it is commonly applied to those with a clearly terminal illness. Indeed, one respondent noted:

> It's all very well to say palliative care, but what does that mean to that family? (Nurse, Emergency Department).

However notwithstanding the observed disquiet with fine definition, a number of respondents felt that children with chronic, but not necessarily terminal, conditions could benefit from the principles of palliative care. One example of this sort of comment was:

> ... some kids need palliative care from the time of diagnosis (Consultant, Neurology Unit).

In addition to the problems of definition, there was some concern, across all disciplines, about what medical interventions were appropriate in the palliative care setting. Issues around hydration, nutrition and medical investigations were most often raised. Some respondents were uncomfortable about what they saw as 'aggressive' or 'unnecessary' procedures. For example:

> ...off the record, others tend to be aggressive in their treatment (Consultant, Cardiac unit).

> ...parents are continually offered false hope, another drug, another drug... [the doctors] are very aggressive not knowing when to stop (Junior nurse, Oncology Unit).

This uncertainty regarding inappropriate intervention surfaced in a number of ways. First, some informants were eager that withdrawal of active treatment should not mean withdrawal of all treatment and in particular, withdrawal of attention. Others suggested that there was general agreement that the transition from a curative to a palliative focus of care was gradual and sometimes unclear in paediatrics, depending on the nature of the underlying condition. Diagnostic and prognostic uncertainties were factors in the delayed identification of children with palliative care needs, with one respondent saying:

> ... recognition of the need for palliative care comes too late in many cases (Consultant, Cardiac unit).

The various patient groups identified as requiring palliative care needs in this study reflected those outlined by Goldman (1990) and described earlier in this paper. Of

particular concern to some were those children in need of organ transplants, who were identified as a very difficult group to manage from a palliative care perspective. For example, treatment while the child was on the 'waiting list' was active and aggressive, but many children died before a donor organ became available.

It was widely believed that the various individuals involved in the care of a dying child became aware of the need for a palliative approach at different points in time. Nursing staff generally felt they identified this point before medical staff, and medical staff in turn believed they identified this point before families. It was suggested by the medical staff that those involved in day-to-day issues were less able to appreciate the broader perspective, as this quote testifies:

> ...nurses may be eager to discuss things when it may not be the right time (Senior Consultant, General Medical Unit).

5.3.2 Level of involvement

The experience of respondents in dealing with children in need of palliative care varied according to their field of practice. At the RCH, nursing, medical and allied health staff, from the neonatal, cardiac, oncology, respiratory and neurology units were more exposed to palliative care issues than others. By comparison most general paediatrician respondents estimated their personal caseload at fewer than five children per year exacerbating the problem of providing appropriate care. One respondent reinforced this difficulty, noting of their own experience:

> ... it's an unusual event in paediatrics and this makes it harder (Consultant, General medical Unit).

For similar reasons, nursing staff respondents from the general units had a very low exposure to palliative care issues.

5.3.3 Communication with Families

Effective communication was identified by many respondents as a strong correlate of the overall efficacy of palliative care. Some nurses felt they needed to advocate for families in obtaining realistic and truthful information. It was their perception that parents usually appreciated a realistic and honest appraisal of the situation as this assisted them in

planning their child's time and care. On the other hand, it was appreciated by both medical and nursing staff that hope was important to maintain and parents did not need 'burdening with the badness of the situation' (Consultant, Neonatal Unit). Parental denial was seen as both a potentially adaptive defence mechanism, and a barrier to effective communication. One respondent claimed that:

> ...family coping skills determine how things go. Some no matter what you say they won't believe it (Nurse, Neurosurgical unit).

According to the interviews, the following factors were identified by respondents as important in facilitating effective communication:

- Time. Respondents said that all discussions with patients and families should be conducted in an unhurried manner with sufficient time allocated for clarification of issues and the answering of questions.
- Private and comfortable surrounds, which are seen as important to maintain a level of professional care.
- Presence of experienced nursing or allied health staff who understand exactly what has been explained to the family. These staff can repeat and rephrase information to the family when the clinician is not available, and provide added insight into the situation which may help to clarify issues for family members.
- Honesty and the use of simple, direct language. It was acknowledged by both medical and nursing respondents that in difficult situations, doctors may take comfort in the use of medical jargon which can often confuse and distress families.
- Empathy, including the need to individualise one's approach to the imparting of information according to the needs of the patient and family.
- Repetition of information and regular confirmation of the family's understanding of the situation.
- Respecting silence and not feeling compelled to fill it.
- Focusing on what can be done for the patient rather than what cannot be done.
- A solid pre-existing relationship between family and consultant

Factors that were seen by respondents as impeding effective communication at the RCH included:

- Lack of time and privacy, with hurried consultations to impart important information to parents being undertaken at the child's bedside or in the corridor.

- Failure to uniformly involve nursing staff in discussions. Although most survey respondents indicated 'satisfactory' utilisation of nursing or allied health staff in discussions with families, there was a discrepancy between the responses of consultants and nurses in that 10% of consultants indicated this to be 'less than adequate' compared with 38% of nurses (Figure 5).

- Discrepancies between the information provided by different staff members. The likelihood of this increased as a function of the number of staff members involved.

- Reluctance to use direct language. For example, respondents identified some parents as not understanding the term 'palliative care' where this term had been used to indicate that their child was dying.

- Diagnostic and prognostic uncertainty. Physician respondents, both senior and junior, felt less able to counsel families in situations where the nature of the child's disease, and its outcome were unclear. It was perceived that this often led to 'false hope' by families as the child's death was often not presented as a potential outcome until late in the disease process.
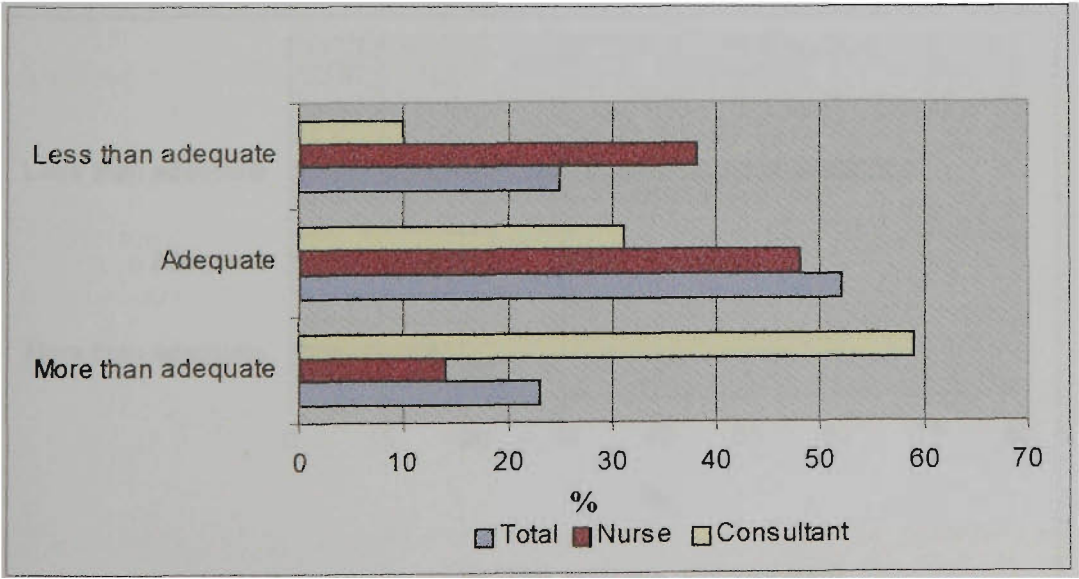
Figure 5: Utilisation of nursing and allied health staff in discussions with families

5.3.4 Inpatient services

A number of themes relating directly to inpatient services, but having an implied effect on services available to patients outside the RCH, were uncovered.

5.3.4.1 Social Work

Social workers were perceived by respondents as readily available during working hours, whilst social work cover was perceived as 'less than adequate' overnight and at weekends. This resulted in the utilisation of social workers who often did not know the families or the disease process, by the medical and nursing staff. Those units with a dedicated social worker found the social work service more helpful than those who did not. Medical and nursing staff respondents commented on the variable skill and experience level among social workers and identified these factors as correlates of efficacy. In addition to the general aspects of their work, social workers were seen as important in facilitating communication and raising parental awareness of the Bereavement Support Group. In some instances they were vital in ensuring parental attendance at follow-up appointments with consultants. Social work respondents reported that some families maintained contact with their social worker well into bereavement. Social workers were seen as valuable in assisting families with financial and practical concerns but the majority of respondents including social workers, were concerned that these supports were inadequate and not uniformly available (Figure 6).
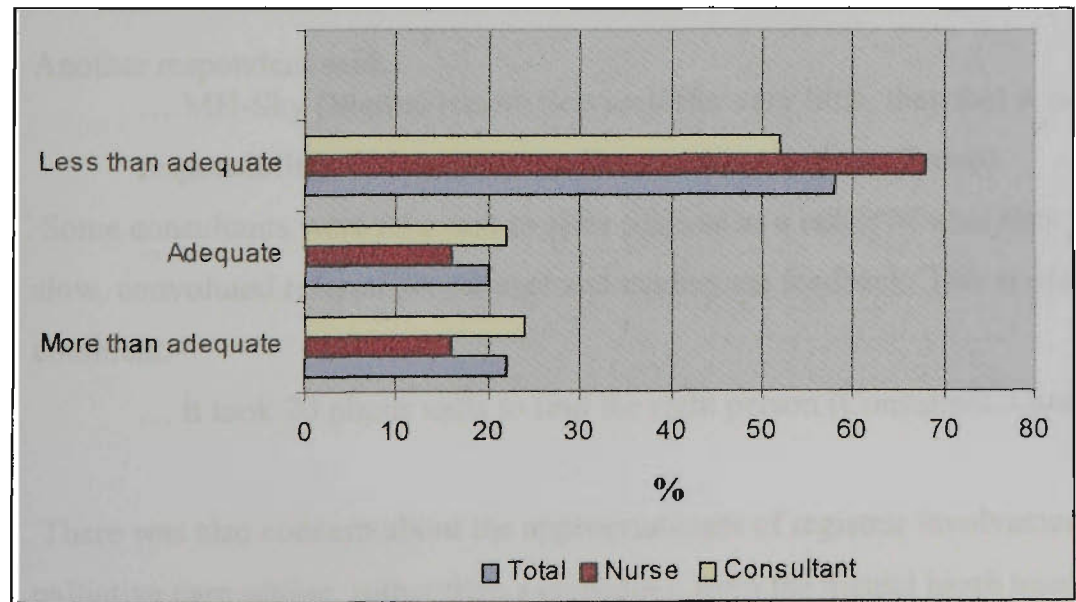
Figure 6: Financial assistance and practical support for palliative care patients

In this regard, some typical comments were:

> ... the unit has dedicated social worker who is very helpful and available after hours if a death is anticipated.... sometimes I try and have the social worker present when bad news is delivered (Consultant, Neurology Unit).

> ...the social workers change frequently and are under resourced (Consultant, Cardiac Unit).

5.3.4.2 Pastoral Care

Respondents generally regarded pastoral care staff at the RCH as being readily available and considerably helpful in supporting both families and staff. Multiple respondents made comments such as:

> ....pastoral care were available and helpful (Medical Consultant, General Unit).

> Our chaplain appears to take on much of the role Social Work should be doing (Nurse, Thoracic Unit).

5.3.4.3 Mental Health Services

Many respondents raised concerns about the responsiveness of the mental health service. One said:

> ...psychiatry [the psychiatry unit] are almost useless... as they use different time frames and provide no feedback, however they are improving (Senior Consultant , Oncology Unit).

Another respondent said:
> ....MH-Sky [Mental Health Service]offer very little, they feel it is not their
>
> responsibility. (Social Worker, Bereavement Support Group).

Some consultants were reluctant to refer patients as a result of what they perceived as slow, convoluted referral procedures and inadequate feedback. This is illustrated by the comment:

> ... it took 20 phone calls to find the right person (Consultant, Cardiac Unit).

There was also concern about the appropriateness of registrar involvement in the palliative care setting, rather than a consultant from the mental heath team. Once engaged, however, the mental health team were generally perceived as helpful to families.

5.3.4.4 Pain Team

The responses obtained during the course of this project indicated that respondents valued the input of the Pain Team highly in the setting of acute or post-operative pain, but that chronic pain was less well-addressed, probably as a result of the pain team's limited resources. There was evidence that there was also reluctance by some consultants to refer patients for to the pain team, for opinions regarding pain management. Difficulties were encountered when there was inadequate communication, goal setting and planning by the 'home team' and one respondent said somewhat bitterly [4]:

> ... conflict is common and detrimental to patient care, as the person with the most power wins (Nurse, Pain team).

5.3.4.5 Care Managers

The appointment of care managers in a number of units around the hospital was seen as improving care through better coordination and community liaison. There were many respondents who made similar statements to:

> ... the care manager on the [***] floor has been a good development (Senior Consultant, Medical Unit). [Identifying information removed by author].

> ... having a co-ordinator [Care manager]works well (Nursing Staff, Neurology Unit).

5.3.4.6 Facilities for care at the time of death

Respondents were divided as to the adequacy of facilities for care at the time of death (Figure 7). While children in the terminal phase of their illness were generally able to have a room of their own, which they could decorate to create a home-like environment, there were concerns about lack of privacy and space. It was felt that in some cases:

> ...the environment is not conducive to a "good death", and the poor facilities led to an increase in parent anxiety (Senior Nurse, Cardiac Unit).

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[4] An extensive review of the management of paediatric pain at the RCH has recently been completed, and a report detailing the findings of that review has recently been released. As a result, some of these concerns now have been addressed.

Whilst extended family members were encouraged to attend, there were often difficulties accommodating them, again as a result of limited space. At the same time, nursing staff tried to be sensitive in their handling of families, going to great lengths to allow them time with their child. They were also aware of the need to adopt a flexible approach with some families requesting to take their child home with them after death.

Regrettably, the viewing room was generally regarded as unsuitable by most respondents, due to it being in close proximity to ambulance bays and emergency department waiting areas. Most nursing staff tried to avoid using it when parents or family wanted to view a child's body, preferring to give extended time to the family in the ward area to allow them to remain as long as they wanted with their child.
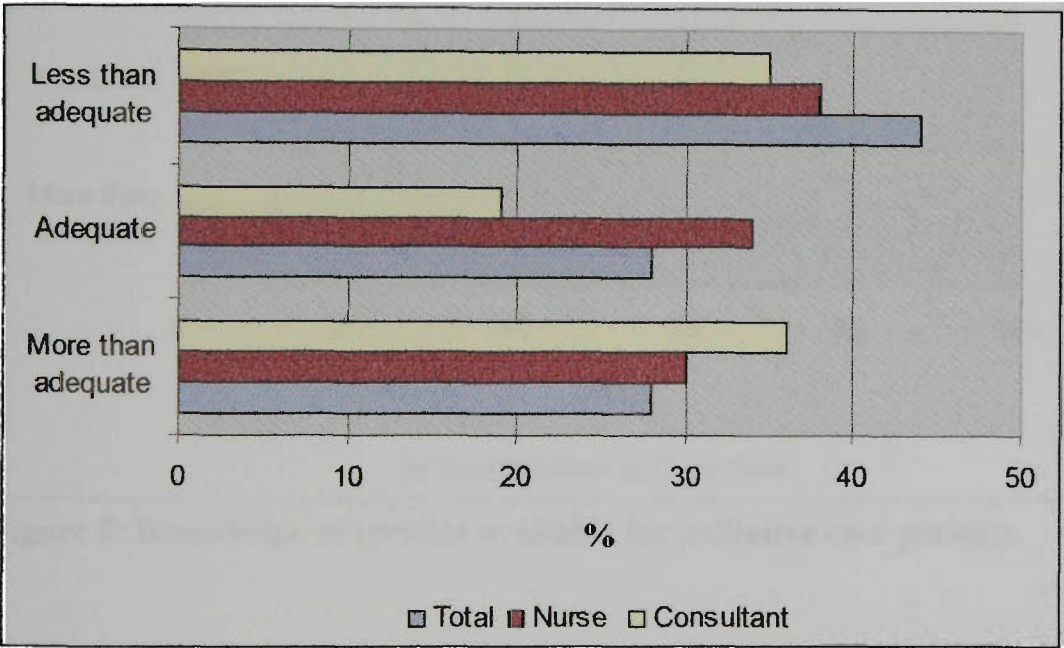
Figure 7: Facilities for the care of children and their families at the time of death

5.3.4.7 Home and Community Care Team

A few respondents had cared for dying children in the home setting, in conjunction with the RCH Home and Community Care Team (HaCC). Most of these reported positively on their experiences:

> ... the hospital-in-the-home nurses were fantastic and supported the family (Consultant, General Medical Unit).

... the Family Choices Program were very helpful in co-ordinating community services. (Consultant, General Medical Unit).

5.3.5 Community Services

This investigation has shown that there was a striking lack of knowledge of, and experience with, community agencies by the respondents (Figure 8). Consider this statement for example:

> I woudn't know how to relate to them...what are they going to add to care that's not already being done (Consultant, General Medical Unit, and Community Practice).
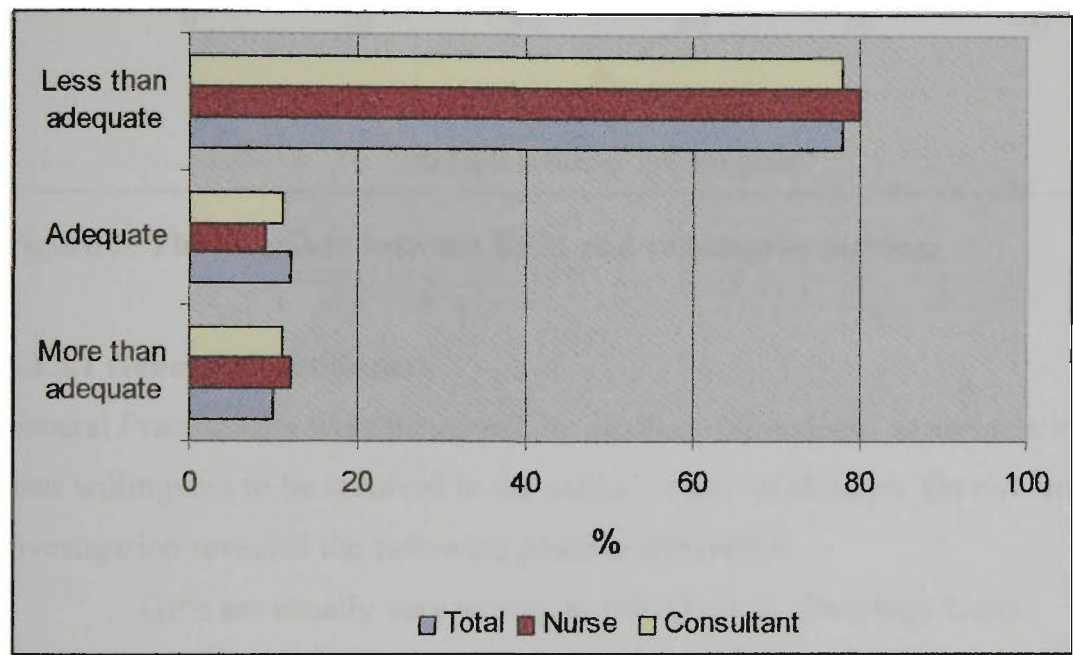
Figure 8: Knowledge of services available for palliative care patients

Nearly 80% of survey respondents identified their knowledge of available services as inadequate. Respondents found home care difficult to organise and many expressed a lack of confidence in the care provided, suggesting:

> ...they are unable to provide a 24 hr service (Consultant, Thoracic Unit).

> ....rural children miss out (Consultant, General Medical Unit).

> ...if the family are rural then the wheels fall off (Social Worker, Oncology Unit).

Links between hospital and community were seen as weak, although nursing staff took a dimmer view of this than consultants (Figure 9).
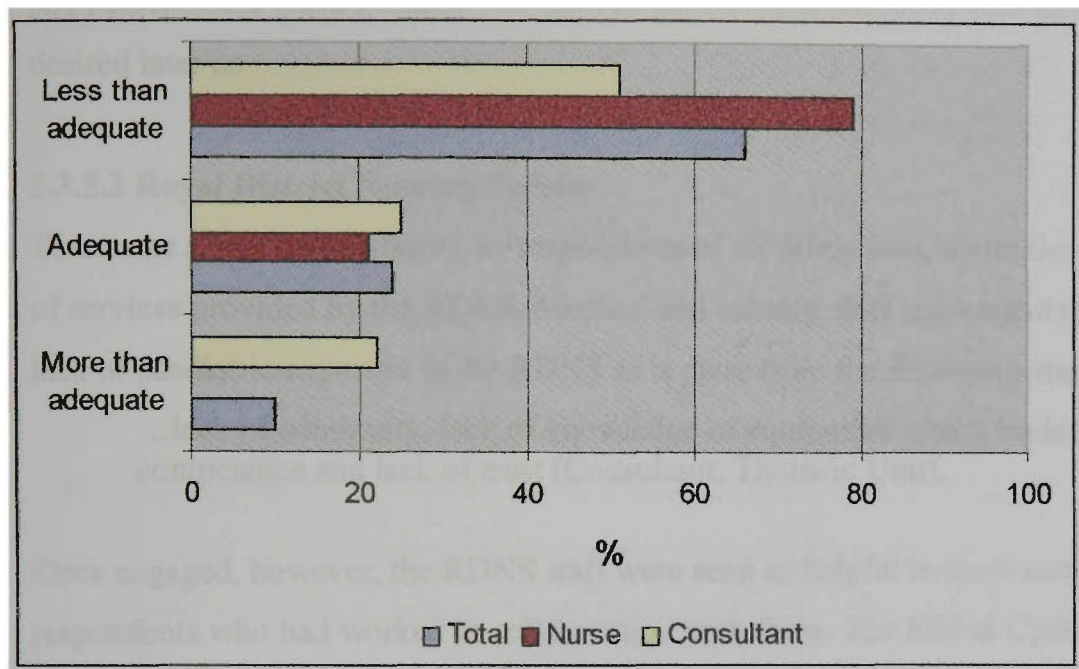
Figure 9: The interface between RCH and community services

5.3.5.1 General Practitioners

General Practitioners were perceived, by medical respondents, as variable in terms of their willingness to be involved in the palliative care of children. On one hand, the investigation revealed the following positive comments:

> ...GP's are usually very willing to help (Fellow, Oncology Unit).

> ...I work closely with the GP (Consultant, Neurology Unit).

However, some consultants expressed concern about the ability of General Practitioners to undertake certain aspects of care due to variable communication and clinical skills as well as time constraints and lack of after-hours cover. For example two consultants noted:

> ...GP involvement is extremely variable, they need a paediatrician's support as their knowledge is poor (Consultant, Cardiac Unit).

> ...individual GP's can be very helpful with home support, although there can be demarcation disputes. It is important to clarify who will do what (Consultant, Neurology Unit).

Overall, fostering a good relationship between hospital staff and the General Practitioner (GP) early in the child's illness was seen as beneficial if palliative care in the home was desired later on.

5.3.5.2 Royal District Nursing Service

There was a lack of familiarity by respondents of all disciplines, about the type and level of services provided by the RDNS. Medical and nursing staff respondents perceived a lack of paediatric expertise in the RDNS as is clear from the following statement:

> ...lack of continuity, lack of knowledge of equipment which leads to lack of competence and lack of trust (Consultant, Thoracic Unit).

Once engaged, however, the RDNS staff were seen as helpful in most instances by those respondents who had worked in collaboration with them. The RDNS Cystic Fibrosis Liaison nurse was offered as an example of a successful link between the hospital and the community as she, although employed by the RDNS, worked within the hospital setting to co-ordinate a community service [RDNS] response.

5.3.5.3 Community Palliative Care Teams

Few respondents had personally referred children to community palliative care teams, but those who had, reported variable experiences. Problems encountered included a lack of paediatric expertise in the community agency staff, and a reluctance by community teams to accept the need for clinical supervision by the child's paediatrician. The uncertainty involved here is clear from these responses:

> ...there are sometimes difficulties using community palliative care teams due to inexperienced staff (Social Workers, Oncology and Neurosurgery Units).

> They [Community Palliative Care Teams] have difficulty with children under 10. I use Hospital in the Home (Consultant, Neurology Unit).

In addition the project has found that RCH consultants, who had experienced these difficulties, were unlikely to refer other children to these services.

5.3.5.4 Very Special Kids (VSK)

Most medical consultants who responded were aware of VSK, but few had referred children to this organisation. Those who had, reported positively on their experiences with both the facility and the service. Unfortunately, knowledge of VSK and services available to families was poor in nursing respondents from units other than oncology and neurology.

5.3.6 Conflict

Conflict between nursing and medical staff around treatment decisions was acknowledged by approximately half of the respondents. Conflict usually resulted from poor communication between medical and nursing staff, or perceptions of overly aggressive medical interventions by nursing and allied health staff. The intensity of this issue is illuminated by the following comments:

> ...conflict is not uncommon between medical and nursing staff. In the end the consultant has to carry the responsibility and so makes the decisions (Consultant, Immunology Unit).

> ... conflict between nurses and doctors is common, less so between doctors as there is a clear line of responsibility.... Nurses are not allowed into the process early enough to express their views, if decisions have been made and there is disagreement ill feeling often results (Consultant, General Medical Unit).

> ..some issues are dodged around and nurses get caught in the middle (Junior Nurse ,Oncology Unit).

Those units who reported a low incidence of conflict attributed this situation to a 'team approach' to decision making and the inclusion by the consultant medical staff of nursing and allied health staff in discussions. Open and honest communication between staff from differing disciplines was seen as helpful, as shown by this comment:

> ...we try to discuss it together before speaking to the family (Consultant, Cardiac Unit).

Notwithstanding this problem of conflict, some respondents, particularly nursing staff, appreciated consultants being open and honest when talking to parents and family members.

In general it appears that where more than one medical unit was involved in the care of a child with palliative care needs, conflict was common. The potential for the relay of inconsistent information to families in this setting was reported to be high.

5.3.7 Home Care

Many respondents, across all disciplines, felt that more children with palliative care needs could be cared for at home if support services for this undertaking were improved. Most consultants liked the concept of home care, but could not see it suiting their particular patients. Some respondents, particularly nursing staff, were of the opinion that home care was not offered in all potentially appropriate cases. For example:

> ...most patients I have been involved with have chosen hospital care, although few have been offered home care (Consultant, Genetics Unit).

> Those that want home care can usually have it (Consultant, Thoracic Unit).

> ... home care is difficult in this group. Once the palliative phase is identified things happen very quickly, too quickly to mobilise things at home or to meet new people. (Consultant, Thoracic Unit).

> ... I wonder whether home care is given as an option in all cases? (Nurse, General Medical Unit).

> ...more children could be nursed at home (Nurse, Oncology Unit).

Current barriers to the utilisation of home care were identified in this investigation as:

- Lack of familiarity with community services and uncertainty about the level of care possible.
- Concern about the possibility of acute deterioration in the child's condition.
- Concern about losing touch with the patient.
- Complexity of care required or need for high-dose opiates.
- Children in rural areas were seen has having access to fewer services.
- Difficulty anticipating needs.
- Concern about families feeling abandoned by the hospital.
- Concern regarding the introduction of new (community based) staff at a sensitive time for the family.

- A perceived lack of paediatric expertise in community palliative care teams.
- Children and families feeling unsafe at home and secure in the hospital environment.

The improvements required to increase the utilisation of home care were identified as:

- Consistent 24hr access, by families, to a responsive and rapidly mobilisable support service.
- Access to nursing staff with paediatric expertise.
- Regular medical review by the child's paediatrician.
- Practical assistance such as respite care, financial support, and home modifications.
- A 'team approach' utilising staff from all disciplines across the RCH and community service providers, to ensure optimum care for the child and family at home.
- Meticulous planning to try and avoid crisis in the home setting.

5.3.8 Decision making and Care Planning

Although most respondents agreed that parents should be involved in decision-making, there was a lack of consensus over the degree to which this should occur. There was some support for early involvement of families as indicated by these quotes:

> ... the earlier decisions are made, the easier it is ....physicians probably need to guide the family quite strongly (Senior Consultant, Community Division).

> ... advance discussion may help avert inappropriate intervention (Consultant, ICU).

Notwithstanding these views the complexity of the situation becomes quite evident as some respondents felt that decisions were ultimately up to the parents, whilst others felt that this responsibility fell to the consultant. There were concerns, by some, about families feeling they (the respondents) had made the decision to end their child's life. For example it was noted:

> ...it's not kind to ask the parents to agree to a DNR [Do Not Resuscitate] order unless its [the outcome] very clear (Consultant, Cardiac Unit).

With this in mind, most consultants strongly guided parents in their decision making but emphasised the collaborative nature of this process. Typical responses around this situation were:

> ... it's a guided decision. For example, our decision is that we should stop treatment then we say to the family "It's our decision but you are part of it" so we take the responsibility (Consultant, ICU).

> ...we need to unhook the family from thinking that they made the decision. I use phrases like " I think we've reached the point where comfort is the priority, do you agree?" (Consultant, Genetics Unit).

In addition, further emphasising the difficulty of this area, respondents were divided as to the adequacy of ethical and legal support in cases where decisions were unclear or difficult (Figure 10).

Many respondents felt that preparing families for the possibility of their child's death was important, but it was apparent that this did not consistently occur.

> ... families are often unprepared for the point where nothing more can be done... by not saying the "D" word (Nurse, Oncology Unit).
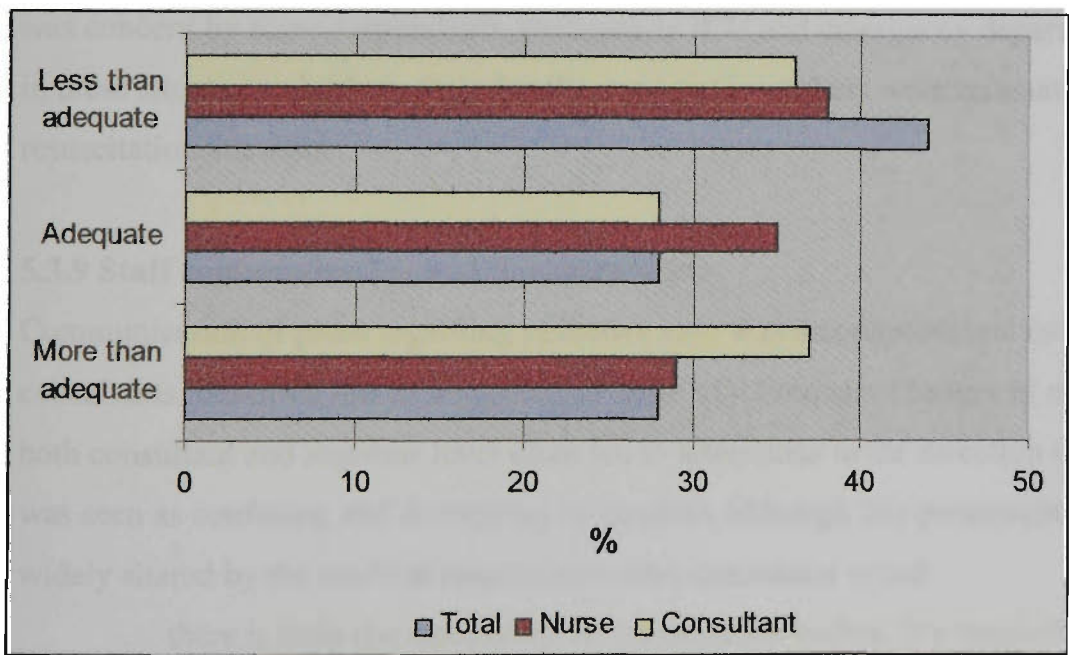
Figure 10: Ethical and legal support for decision making and conflict resolution

Some respondents felt that families were very aware of the likely course of progression of their child's disease from their experiences observing other patients on the ward. However, most respondents felt parents were unfamiliar with terminal symptoms and were seen as needing more information about these. The difficulties of raising these issues when the child was stable or well, were widely acknowledged. Outpatient appointments were also not seen as conducive to such discussions. Although planning was identified as important, respondents gave evidence that it did not regularly occur with some families presenting to the RCH emergency department in a confused and panicked state. One respondent observed that:

> ...it is one thing to agree on a plan when the child is well, it's another to follow through with this during an acute event (Consultant, General Medical Unit and Private practice).

In these situations, families were unable to relate their wishes to the emergency department treating team, either because there had been no prior discussion with the 'home team' or they were in a state of emotional upheaval. Unit records were difficult to retrieve quickly and the documentation contained within them was often limited. There was concern by some respondents, particularly ICU and emergency department staff, that in these situations children, their families and staff members were traumatised by futile resuscitation attempts.

5.3.9 Staff communication and documentation

Communication of plans regarding palliative care was inconsistent and more nurses than consultants identified this as a problem (Figure 11). Frequent changes in medical staff at both consultant and registrar level often led to alterations in the direction of care. This was seen as confusing and distressing to families, although this perception was not widely shared by the medical respondents. One consultant noted:

> ... there is little documentation of resuscitation orders, it's implicitly understood (Consultant, Thoracic Unit).

Documentation in the unit record was generally inadequate, and although a proforma had been generated for the purpose of detailing plans for treatment in the event of a crisis, many respondents were unaware of its existence. Some were uncomfortable with the

concept of using a proforma, especially with the requirement for a parental signature, as this comment testifies:

> ...I'm happy with the documentation, but not for parents to sign (Consultant, Neurology Unit).

Respondents from a number of units felt that efficient verbal handover between unit staff obviated the need for such documentation, and they reported that the verbal handover process worked well. Other respondents reported this was not the case, however, particularly in situations where unfamiliar staff members were likely to be encountered as the child moved between units, such as transfer to the ICU.

Generally, respondents felt that the current documentation and communication processes around palliative care issues was inadequate (Figure 11). One relatively junior respondent indicated that he felt:

> ... there is poor documentation and people are afraid of broaching the topic with the family.... word of mouth doesn't work (Junior Medical Staff [Registrar], Oncology Unit).
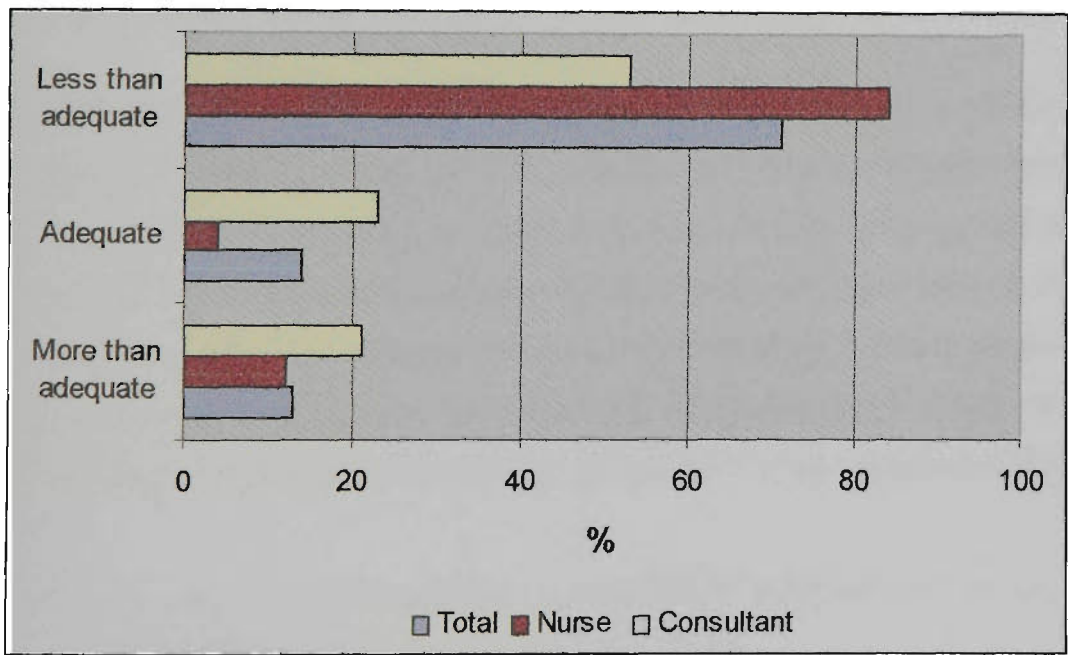
Figure 11: Communication and documentation regarding palliative care patients

Suggestions were made regarding interventions which may improve communication:

- Utilisation of the 'alerts' system in the Emergency Department to flag, at the triage stage of admission, those children receiving palliative care.

- Utilisation of a proforma document, placed in the child's UR, detailing treatment plans in the event of a crisis, with copies given to the parents.
- Inclusion of nursing and social work staff in discussions with families.
- Detailed handover between staff at all levels and across disciplines.
- Availability of a staff member familiar with the child's current and planned care, at all times.

5.3.10 Staff support

Many respondents spoke of a 'heavy toll' in dealing with palliative care patients. Most found sudden, unexpected deaths especially difficult to deal with as these comments show:

> ... I hate finding out in handover that such and such had died this week (Junior Nurse, Oncology Unit).

> ... when pain management is going badly it's stressful (Nurse, Oncology Unit).

It was widely believed that peers provided the most important source of support.

Nursing staff utilised two methods of support within the hospital environment. First, formal debriefings. These were best attended and most useful when arranged soon after significant events, regular meetings were not successful. Nursing staff found debriefings helpful but it was emphasised by some, that issues relating to aspects of management should be dealt with separately where possible. Second, informal support. This was very important to many members of the nursing staff as this allowed them to seek out compatible personalities and to deal with issues in a way that suited them.

Junior resident medical staff respondents (RMO's) felt that they were a neglected group as far as staff support was concerned. One noted:

> There is very little[support] for junior medical staff, with little involvement of doctors in debriefings (Registrar, Oncology Unit).

In addition, this group felt excluded from nursing debriefings and, although consultant medical staff expressed a willingness to provide support, many residents felt unable to approach their consultants.

Consultant medical staff respondents reported that they were reluctant to discuss their emotional experiences around palliative care issues with other staff, particularly those from other disciplines. Some suggested that they did not wish to appear 'vulnerable'. Some consultants felt that this pattern of behaviour provided a negative behaviour model for junior medical staff and were concerned about that. Senior medical staff responded that they were unlikely to use the staff psychologist and most could not see this as being helpful, preferring to deal with their issues in a 'private' manner. There were a number of statements made indicating that this was truly felt, for example:

> ....I keep a bottle of scotch in my office drawer for such occasions....
> (Consultants, Neonatal unit & Oncology unit).

> A good strong cup of tea (Fellow, Oncology Unit).

> ... there is a sudden increase in the number of medical staff seeking help and more medical representation at debriefings (Consultant, Staff Support Service).

In addition, a small number had sought the support of a particular senior consultant who is known to have an interest in this area of staff support, and had found this extremely useful.

Patient Services Assistants and other allied health staff (physiotherapists and occupational health therapists) were identified as another neglected group. These staff members often formed close relationships with children and their families, but were not regularly informed of deaths or changes in condition, nor were they encouraged and supported to attend debriefing sessions.

Many respondents were not aware of the existence of the staff psychologist, although those who had utilised this service had found it helpful, as this comment by the staff support consultant shows:

> ... I refer on 10% [of staff] to specialised psych services or grief counselling services (Consultant, Staff Support Service).

However, some respondents were concerned about confidentiality issues with the staff psychologist.

5.3.11 Bereavement Care

The RCH Social Work Department runs a Bereavement Support Group (BSG) of which most respondents were aware. There was, however, a lack of knowledge by respondents of the services provided by the BSG, and in particular, the means by which parents are notified of its existence, together with the lines of referral to community based services available for those who are unable to attend (Figure 12). A senior respondent noted:

> ...we need more involvement in bereavement care (Senior Nurse, Oncology Unit).

Many respondents expressed concern that parents may find it difficult to return to the hospital after their child's death and that group therapy may not appeal to everyone.
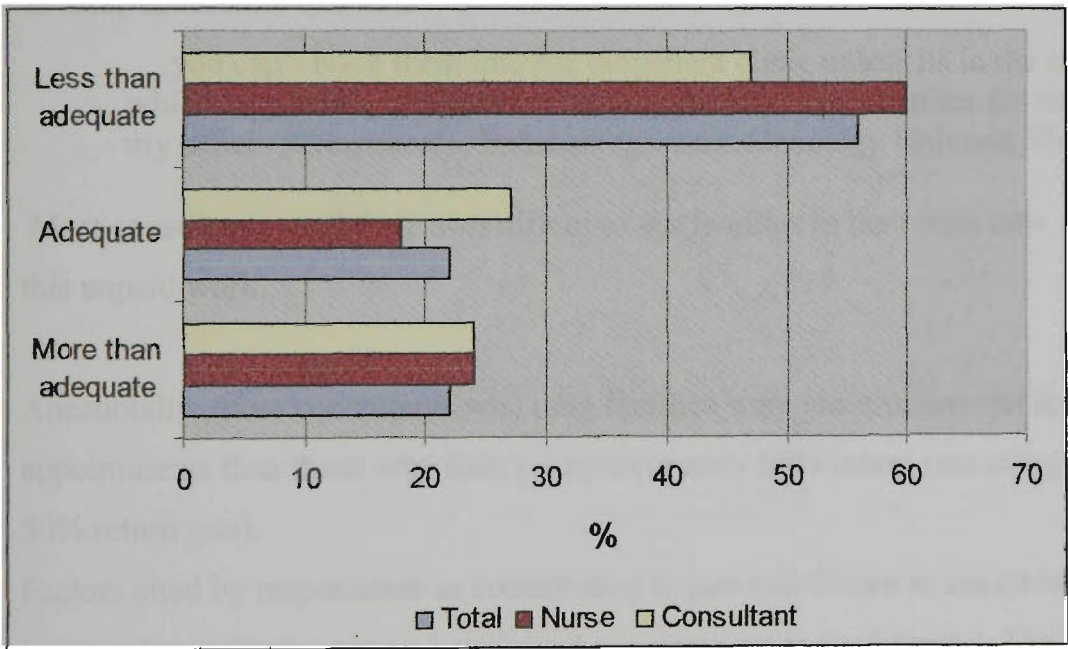
Figure 12: Knowledge of bereavement services available to families

Follow-up appointments with bereaved families were made according to individual consultant practices. Most consultant respondents wrote letters to families offering appointments. A smaller number rang bereaved families routinely, or if the family did not make contact with them after receiving the letter. In some circumstances, the unit social

worker facilitated meetings between the family and consultant after the death of the child. The content of the follow-up appointment varied according to individual consultant practices but most consistently included a discussion of the child's management, a review of any unanswered questions and a report on the post-mortem examination (if any). Few consultants discussed issues relating to grief and most felt inadequately equipped to detect or deal with profound grief. This is illustrated by the following:

> ….I'm not confident about spotting a family experiencing pathological grief or where to send them (Consultants, General medical Unit; Thoracic Unit; Cardiac Unit).

> … what they [families who are not coping] need is very individual in terms of [grief] supports (Consultant, General Medical Unit).

The outpatient setting was widely seen as an inappropriate setting for these discussions, as these comments illustrate:

> …you can't book them into the outpatient clinic unless its in the child's name which may result in distress. There ought to be a mechanism for this. I see them in my office. (Consultants, Immunology Unit, Oncology Unit and Thoracic Unit).

Most consultants used their own offices to see families in their own time and considered this unpaid work.

Anecdotally, those consultants who rang families were more successful in achieving appointments than those who didn't (approximately 80% return rate compared with a 50% return rate).

Factors cited by respondents as contributing to parental failure to attend included cultural issues, place of residence and anxiety about returning to the hospital. The fate of those who did not return was unknown, but it was felt by many respondents that they potentially represented the most needy group. One view was that:

> …middle class people accept their appointments, lower classes less so, especially ethnic groups. I don't know what happens to them….. I worry about those who don't come along (Consultant, General Medical Unit and Private Practice).

5.3.12 Research and Academic activities

Respondents reported that three units had undertaken, or were undertaking, research in this area. In 1983, a palliative care project was undertaken between the Haematology/ Oncology unit of the RCH and the Royal District Nursing Service (Norman *et al.* 1986). The Haematology/ Oncology unit had also studied family adjustment following bereavement (Jurk *et al.* 1981). Nursing staff in the Intensive Care Unit are currently studying bereavement issues in their patient group. The Neonatal unit is currently undertaking research into the palliative care needs of families with severely neurologically damaged neonates.

Other units have descriptively reported their experiences (Rogers, 1994; Carr-Gregg *et al.* 1997; Meehan, 1999; Sawyer, 2000) and the sixth edition of the hospital's paediatric handbook contains a complete chapter on death in childhood (McDougall, Rogers, van Doorn & Loughnan, 2000). One hospital consultant has a special interest in grief and life-threatening disorders and has given seminars on these topics to nursing, medical and paramedical staff. Another has given seminars to students undertaking the Postgraduate Diploma of Palliative Medicine at the University of Melbourne.

5.3.13 Barriers to the provision of palliative Care at the RCH.

The following factors were identified by respondents as impeding the provision of palliative care to patients of the RCH:

- Hospital-focused care with poor community links and an unwillingness to offer all options to families.
- Disease-focused care with insufficient attention paid to symptoms, emotional issues and quality of life.
- Difficulty dealing with the concept of death in childhood leading to a reluctance to discuss the topic in an open and constructive manner. This influences communication patterns between staff and families as well as between staff members.
- A lack of training and professional development, in palliative care issues, at both undergraduate and postgraduate levels for both medical and nursing staff.
- Poor communication and documentation.

- Lack of direction and planning.

- Lack of coordination. 60% of respondents described this as inadequate (Figure 13).

- Lack of knowledge of the community support services available to children and families with palliative care needs.

- Late identification of children as having palliative care needs.

- Ethical concerns regarding the appropriateness, or otherwise, of medical interventions in the palliative care setting.

- Conflict between units regarding patient management.

- Lack of privacy and adequate viewing facilities.

- Time constraints.

- Reluctance to use adequate doses of opiates in symptom management.
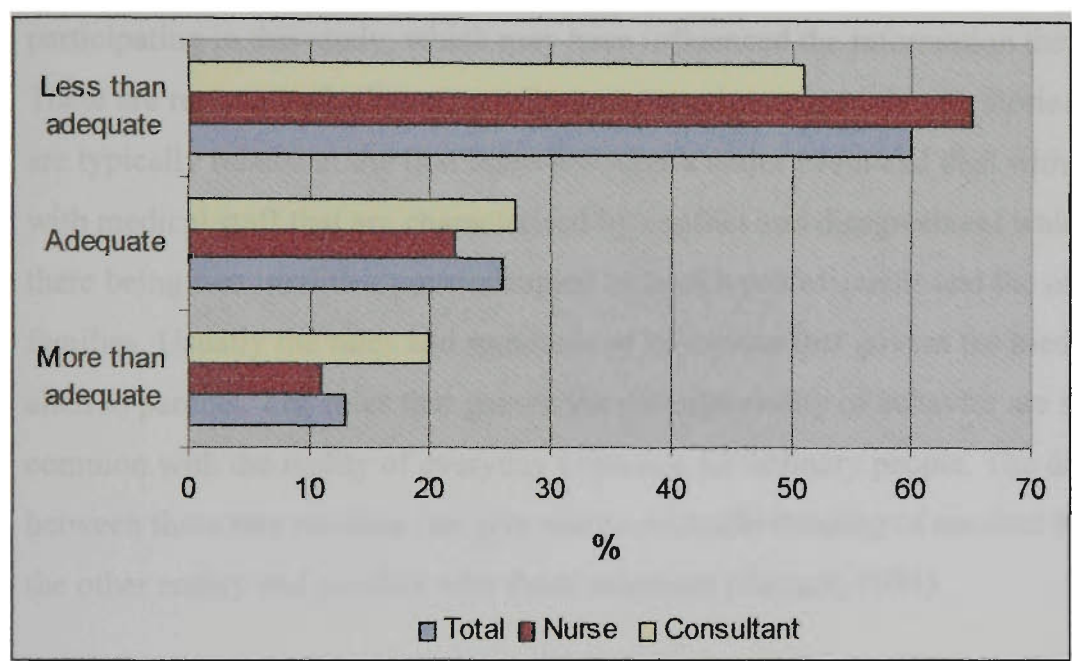
Figure 13: Coordination of RCH services for patients with palliative care needs.

A number of respondents felt that the generation of a resource around issues to consider, in the care of palliative care patients, by staff members, would be very helpful. Some suggested:

> ... I would be keen to have a checklist of issues to think through if palliative care is required (Consultant, Cardiac Unit).

> Some guidelines for care would be good. What to say, Where to be and How to do (Nurses, Cardiac Unit).

Some respondents felt that the existence of a dedicated service within the hospital would increase the profile of palliative care issues thereby influencing practice and encouraging open discourse on the topic, saying:

> ... it would be helpful to have access to knowledge of services available and a person who could coordinate those services (Consultant, Immunology Unit).

> ... yes it would help to have access to expertise in palliative care (Senior Nurse, Neonatal Unit).

5.4 Parent interviews

Although families were chosen randomly, some may have had particular reasons for participating in this study, which may have influenced the information they provided. There are reports in the literature of parents' need to relate 'atrocity stories'. These stories are typically related at the first interview after a major event and deal with encounters with medical staff that are characterised by conflict and disagreement which results from there being two 'realities'; one occupied by health professionals and the other by families. Usually the rules and standards of behaviour that govern the medical reality are alien to parents. The rules that govern the parental reality of behavior are shared and in common with the reality of everyday existence for ordinary people. The differences between these two realities can give rise to misunderstanding of conduct by members of the other reality and conflict with those members (Baruch, 1981).

The quotes used in this section are taken directly from the interviews, and as such, are from the families' perspective of their particular child's illness. Although parents were interviewed at least three months after the death of their child, the responses obtained will almost certainly have been influenced by grief.

5.4.1 Response rate

Forty-five families were approached for interviews, with eight acceptances. Reasons for non- acceptance were not explored unless information was volunteered. Several families declined because one partner felt unable to participate. Eight families had moved from

the address at the time of death and were not contactable. Fourteen families failed to respond to the initial letter or phone call.

5.4.2 Themes from parent / family interviews

A number of themes emerged from the family interviews, with some closely allied to themes that emerged from the staff interviews and focus groups, and those identified in the literature review. Many of these themes received both positive and negative comments from the families.

Table 4. Patient Characteristics

Patient No	Unit	Place of death	Utilised Palliative Care agency
1	Cardiac	RCH	No
2	Oncology	RCH	No
3	Cardiac	RCH	No
4	Oncology	Home	Yes
5	Oncology	Home	Yes
6	Neurology	Home	Yes
7	Gastroenterology	Home	Yes
8	Neurology	Home	Yes

5.4.2.1 Symptom Control

Symptom control was not identified by the families in this study as a problem, with all families commenting positively on the care their child received in terms of pain relief, provision of medication, respiratory problems and seizure control. Only one family commented that pain control had been sub-optimal, due in part to the rapid progression of their child's disease and their lack of involvement with a health care agency at the time.

5.4.2.2 Information and Communication

The collective experiences of the parents interviewed closely mirrored the issues identified in the literature. Various factors emerged from the interviews. Communication, openness, empathy, time, and the opportunity for repetition were all appreciated by parents. The presence of unfamiliar staff members, interruptions, unplanned or hurried

interviews and evasive statements were seen as impediments to communication. Parents who received a clear statement about treatment options and changes in direction from cure to palliation believed that this was very important and beneficial to them in formulating their own plans, even though the news was devastating to them at the time. Those parents who did not receive a clear statement about treatment options and plans believed such a statement would have been of benefit to them.

Access to paediatric consultants was viewed positively, with six out of eight families specifically commenting on positive aspects of their involvement. Four consultants had given parents their personal phone numbers to facilitate 24 hr support and this was very much appreciated by the families concerned.

Openness, empathy, time and repetition are all features of palliative care that were reported on positively by respondents. The following quote illustrates some aspects of 'best practice' as it relates to communication:

> … he [paediatrician] actually asked us to come into the hospital, set up an interview, and he also, which I was really happy about, set up another interview or appointment with us after that , because he said - of course this is shock information, there will be questions that you will have, so when you go away and think about it then you can come back and …. So I felt that was really helpful. He was straight down the line with us which I really appreciated (Mother, Case 8).

The situation referred to above contrasts with what occurred months later when this same family received news, from a different paediatrician, that they had a second child with the same diagnosis:

> …I got a phone call at home 6-8 weeks later from my paediatrician, he was the one who admitted me, who I felt like the paranoid mother, and he said that [*] was fine and he said that [**] also had this disease, and I just went into shock…. if I had been someone who couldn't cope, being a single mother by herself with kids being told like that, over the phone, I think was not right. I think I went into shock probably for that week (Mother,Case 8). [Identifying information removed by author]

The following quotes illustrate factors that were identified as being impediments to communication. One family with a child who moved from a curative mode of treatment to a palliative care mode, described evasive statements about the change of direction:

> …..all I'm going to say is at the actual point of time that "R" shifted over from treatment to palliative care. He [paediatrician] didn't have the balls to say sorry [Doug] and [Dianne] but there is nothing more the hospital can do for you (Father,Case 5). [Names changed by author]

> All I'm saying is, that if a line in the sand had been drawn earlier on, we could have had a lot better quality of life….. if we had known that it was that sort of period of time - I mean three weeks before he died we still hadn't been told that he was going to die (Mother,Case 5).

The mother of a boy speaking about how her son's diagnosis was imparted to her identified factors that were detrimental to effective communication such as lack of empathy, failure to provide adequate support in the form of a relative or nurse, and the presence of an unfamiliar staff member:

> …..the doctor that was looking after him came in with another man, who I'd never seen, and told me that my son was dying, and it destroyed me at the time.. I had no idea of what they were going to say, there was no nurse, there was nothing. And I had to ring my husband and get him to come in (Mother, Case 7).

Two families commented on the lack of time set aside for communication by staff from all disciplines:

> … the hospital system seemed to treat everything very much on a physical level, and for whatever reason the nurses just don't have time to spend time letting people tell their stories, it's a feeling of alienation or the enemy through all parts it's just this animosity and bad air about the whole thing….and I'm not saying that it's anyone's fault it's just something that should be looked at (Mother, Case 4).
> ….we were assigned a social worker who was a waste of time, an absolute waste of time, the only thing she ever said to us was- "I'd really like to help you but I can't right now, I have another meeting"- and she'd go off. I felt like dropping this woman from the [***] floor window many many times (Mother, Case 7). [identifying information removed by author]

The palliative care literature review highlighted the importance of sympathetic communication with families. Two families expressed concern about the way they were treated at the time of their child's death:

> ...the last time she left, the nurse left the door open, and I saw the doctor that was giving [*] the blood test walk past crying, and then out the front of the door and over a little bit, I heard the doctor and nurse talking, like having an argument, she was saying she would tell us he had died , and he was saying no I will tell them...so when they came in they didn't have to say anything, [that my son had died] they didn't have to say anything because I got the point (Mother, Case 1). [identifying information removed by author]

> ....we were standing by the basin washing our hands, three of the nurses I don't know if there was a doctor as well, there was like three staff behind me and they told me, like straight out of a bloody TV show. There really is no easy way of telling someone that their child has just died, but sort of it was like out of ER or something (Mother, Case 3).

> ....even mum said that the social workers were getting a little bit annoying, they kept walking in , sort of give a bit of a knock and walk straight through the door, and kept giving us these pamphlets on what to do when your child dies... I was just content to sit there for as long as it took until I was ready to go home (Mother, Case 3).

Three families expressed feelings of powerlessness in their dealings with staff. One mother was reluctant to request assistance with the care of her child for fear of reducing her chances of discharge. Two families specifically described reluctance to ask questions or make their feelings known for fear of compromising their child's care:

> ...you feel like you're in somewhere totally foreign and you just think that you are going to be consumed with everything that they're saying to you and sometimes you don't think and sometimes you just listen to what they are saying and you think he is just talking rubbish.....and you're so scared to say anything because that person has your child's life in their hands and it's so easy to upset somebody and not mean to...and your so scared and so petrified of what the future is going to hold (Mother, Case 7).

> ... you [hospital staff] have done this a million times before but for each family it's all a brand new thing and it's the most precious thing in the world to you and

you are frightened to say the wrong thing, you're frightened to say how you really feel because you don't want to jeopardise your child's treatment.(Mother, Case 4).

5.4.2.3 Planning and coordination of care

Many parents commented on the lack of planning of palliative care. Some families were discharged from the hospital with what they perceived as inadequate support. Utilisation of community resources appeared to be instigated by parents rather than by hospital staff. Three families of children who received palliative care from a community agency stated that they were the ones who initiated contact with these services:

> …there was no treatment…there was nothing, there was nothing, like that's it, there was nothing. The only thing was just make an appointment, he [paediatrician] just wanted to monitor their progress (Mother, Case 8).

> … when we consulted the hospital we were led to believe that nobody was aware that [*] was in palliative care (Father, Case 5). [Identifying information removed by author]

As described in the literature, three families described the slow pace of learning about the range of resources, supports and care options available:

> … we weren't aware until his third or fourth visit to the hospital that there was home help available. I had to do everything (Mother, Case 7).

> …there was no follow up that day, there was no follow up for the next four or five weeks (Mother, Case 6).

> …I actually didn't really realize that I had choices, I wasn't given those choices or options (Mother, Case 8).

The presence of 'key workers' or case managers was seen as a catalyst to better utilization of community agencies. Two families identified a key worker and commented that the presence of such a person greatly increased their feelings of security:

> …..if we had any questions we could always call [doctor] on his pager. He would always ring back….he connected us to family choices, he wrote the letter, he connected us to VSK (Mother, Case 6).

> …I had a case manager, she did everything… (Mother, Case 8).

Two families stated that they had written plans of care, formulated in conjunction with staff at the RCH and this gave them a greater feeling of security:

> … I showed them [the ambulance] the ' no resuscitation' order, I showed everybody because I didn't want anybody to resuscitate (Mother, Case 8).

> …they [Community palliative care team] had a care plan, and everybody was aware of it, so that was a good and important thing (Mother, Case 7).

5.4.2.4 Practical and Emotional support

Parental comments about practical support were varied, with five out of the eight families expressing great relief at being supported by a community agency:

> …when I left the hospital system, that's the first time I came across people that were really there for us on all levels…… they [Community palliative care team] gave us a feeling of control. They gave us a range of options to enable us to keep her at home (Mother, Case 4).

> …they [Community palliative care team] were the sort of people who would come in and they were there for [**], but they gave time to the rest of us as well (Mother, Case 8). [Identifying information removed by author]

Other families however expressed difficulty in engaging community agencies:

> …I thought the thing that annoyed me most was, they [Community palliative care team] never met her, they never saw her, they didn't assess her, they never met us…. A letter was sent saying what she was and wasn't doing, what we were looking for funding for, and from that they rejected us (Mother, Case 6).

> … I rang the palliative care organization and they rejected us, saying they don't look after children. A week later I rang again and they refused, again saying we don't look after children. It was only after I said that I was desperate that they realised how much I needed help (Mother, Case 7).

Two of the five families engaged with community agencies commented they were stressed by a perceived lack of paediatric expertise within the community agency:

... her [palliative care nurse] experience in dealing with a child with cancer was very limited, she wasn't able to help us in any other way than what we could do to help ourselves (Father, Case 5).

...they [Community palliative care team] didn't know how to look after children, and information that I needed to know they didn't give it to me properly, it was wrong, and because it was wrong the children suffered more, and I was very angry about that (Mother, Case 8).

Practical assistance was described by three out of eight families as satisfactory. This was provided by services both from within RCH, and from community agencies:

...the best thing they [Community palliative care team] supplied was a 24hr phone line, so during the night at anytime I could call them and they would be right there...always a nurse, I needed a nurse, you couldn't send a volunteer (Mother, Case 8).

... we were connected, she was involved in an early intervention programme, and through there into the family choice programme. They supplied a tumbleform chair and a bath chair, that sort of thing (Mother, Case 6).

....he [second doctor] took over from my regular doctor at the end, as [doctor] was on leave, he was wonderful, he organised an apnoea mattress for us (Mother, Case 7).[Identifying information removed by author]

5.4.2.5 Bereavement Care

Statements about bereavement care were mixed. Six of the eight families were offered follow up appointments with their consultant and all attended. One family who did not receive an appointment, organised one themselves at a later date. All families stated that they received the bereavement group newsletter, although only two families had actually attended a meeting. Four families organised their own bereavement support with agencies outside the RCH. Families who had received palliative care from community agencies commented that bereavement care needed to incorporate those carers that had been involved in the process of providing palliative care. Seven of eight families believed that the bereavement support provided to them had not met their needs but they were unable to define this in more specific terms:

...the people that you really need to see [after your child's death] are the ones that were in your home and close to your child, your carers, because otherwise it just cuts off... and you need ongoing support but you don't need medical support (Mother, Case 8).

...when your child does die, and there's no nurses, no palliative care people and there's no-one else, you sometimes get lonely... and you think to yourself now what do I do? (Mother, Case 7).

5.6 Summary

There were a number of themes identified similar to those outlined in the literature, by both staff and parent respondents. It would seem from the results detailed above, that problems with defining palliative care, and establishing when it should be introduced in the child's continuum of care, contribute significantly to difficulties encountered at the RCH. Communication issues between individuals, teams units and organizations also contribute in a major way to the difficulties involved in providing care for this group of patients at the RCH. Communication between the various health professionals involved and the families seems also to be less than optimal. There are however responses from both staff and parent respondents that detail examples of good practice that can be used as guides to improvement. The themes from the research, when viewed in the context of Corr's(1992b) task based model, would seem to indicate the areas, or tasks, that require input from various staff members both within the RCH and in the community setting to accomplish. The next chapter will discuss the findings and present some suggestions for strategies to help accomplish some of these 'tasks' hopefully leading to improved care for children and families who require palliative care.

Chapter 6 Discussion and Recommendations

6.0 Introduction

This research investigated the practice of paediatric palliative care in a major Australian hospital, focussing particularly on the perspectives of, and the interactions between, individuals involved in a range of cases. This section will deal with the interpretation of the findings in the context of the theoretical frameworks outlined in chapter three. Whilst some recommendations will be made as to the development and practice of paediatric palliative care at the RCH, by inference these recommendations may also apply to other tertiary paediatric health care institutions. In the last section, the limitations of the study will be discussed, and some brief suggestions of possible extensions to this work will also be presented.

6.1 Discussion of themes from the research.

This section will deal with discussion of the themes that emerged from the research and make recommendations to improve those areas as they pertain to the RCH, and, by inference, to other appropriate health care settings.

6.1.1 Information sources relevant to paediatric palliative care.

Given the large number of children that are admitted to the RCH each year, it is remarkable, and somewhat gratifying, that only a small number of paediatric patients die each year. Table1. indicated that, of patients of the RCH, 225 children died from all causes in 1998-99. Excluding deaths from acute causes, there were approximately 167 children and families who may have potentially required palliative care in the study period. These cases were distributed across a number of clinical units within the RCH, making the point that the majority of RCH staff will have had little experience in dealing with palliative care issues. Similarly, in the community setting, approximately 50 children across Victoria died in the study period. Because of the small numbers of cases involved in both the institutional or community settings, it is clear that staff working with paediatric palliative care have limited exposure to the issues associated with caring for dying children and their families.

Against this background, it is perhaps surprising that there is no statement contained within the RCH mission and vision statements or philosophy of care that defines palliative care as it applies to children. In the light of the low patient numbers and resulting low exposure to palliative care issues, it is not surprising therefore that many hospital staff have no clear reference point on which to base their decisions and attitudes that underlie their provision of palliative care to patients of the RCH. Consequently, staff members from all disciplines are required to draw on experience and knowledge gained from other settings to support them in their provision of palliative care. The drawback of this approach is that the theoretical underpinnings that inform the provision of palliative care in paediatric settings may be significantly different from that of their colleagues in adult medicine. These differences can give rise to conflict, tensions and poor communication not only between staff members, but also between hospital staff and patients and their families. As illustrated in earlier sections of this thesis, these experiences with adults may not extrapolate into the paediatric sphere for a variety of reasons, including the developmental differences, both psychological and physical between children and adults, and the differing involvement of the family in the palliative care matrix.

In this study, staff and parent respondents indicated that, often, the identification of children and families as requiring palliative care was delayed or non existent, and this had implications for both the care of the child and family during the latter stages of his or her illness, and the management of the family during their bereavement. There is some suggestion that this may have been due in some cases to staff members' minimal previous exposure to palliative care issues. This may also be exacerbated by the fact that there exist no clear definitions and appropriate theoretical underpinnings of palliative care in place at the RCH. Consequently, it would seem prudent for the RCH to define in detail the concept of palliative care to be utilised, and the theoretical concepts that underpin such a definition, and to make this information readily available throughout the hospital to all staff who may become involved in caring for a child and family who require palliative care. In addition, such information should be readily obtainable, in an appropriate form, for both patients and their families, should they wish to seek it out. This would provide a clear reference point for all those involved in the palliative care process, as deliverers and receivers of care, to use as a basis for action and decision making.

The definition used by the Royal College of Paediatrics and Child Health, in the UK, and ratified by the Association for Children with Life Threatening or Terminal Conditions and their Families (UK), is broad, and would seem to address several of the necessary areas as identified in the literature review and staff and parent interviews. It suggests:

> Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement. (Royal College of Paediatrics and Child Health & Association for Children with Life-threatening or Terminal Conditions and their Families, 1997)

Notwithstanding the broad scope of this statement, it is felt by the author that, in the current cultural and political climate, it is not enough for this definition to be simply transplanted and used at the RCH. Based upon the findings presented in this paper, the author would recommend that paediatric palliative care at the RCH be defined as: The comprehensive care of children with conditions from which there is no reasonable hope of cure and from which they are likely to die. This care includes symptom management, emotional, spiritual, practical and bereavement support for the child, family and staff members to effect optimum quality of life.

The author feels that the definition utilised by the Royal College of Paediatrics and Child Health & Association for Children with Life-threatening or Terminal Conditions and their Families, whilst comprehensive in its description of the scope of care to be provided, has implicit within it the notion that palliative care is a one way process and that the 'health-professional care providers' involved in providing palliative care are in some way untouched by the process and are not in need of care themselves. This definition is also compromised, the author feels, by the use of the term *life limiting conditions,* which could be seen to include conditions that a child may suffer from that may not result in death but have severe life limiting effects on the quality of the child's life rather than the quantity. The author would contend that such children would need care that is similar to palliative care but is fundamentally different, in that the underlying intent of such care would be to ensure an optimum

quality of life for the child and family rather than an optimum death. The author feels that his definition is more palliative care process orientated in that it specifies that the child is likely to die as a result of its disorder and that it is more inclusive of all who are involved in the palliative care process.

6.1.2 Relationships between RCH and community service providers

The findings of this thesis also reveal a general lack, in RCH staff, of detailed knowledge of community service providers' availability and capabilities in regards to the provision of palliative care. In the past, the RCH has suffered some criticism, by a range of community service providers, for being somewhat too insular in its approach to patient care. The findings of this study would seem, at first glance, to be in accordance with that view, with respondents noting the weak or non-existent links made by the RCH between the hospital and palliative care service providers in the community setting. However, on deeper analysis, this finding may be viewed as a failure of a two-way interaction between the RCH and community service providers. Indeed, some staff respondents described how home care for patients was 'difficult' to organise. Whilst this difficulty may indeed be a reflection of the lack of knowledge by RCH staff of palliative care services that are available in the community to support or deliver care to patients and their families at home, it may also be reflected in the views held by many RCH medical consultants and nursing staff that community palliative care providers either have little or no expertise with, or display some general reluctance in caring for, paediatric patients. This perceived reluctance could be reflected in the lack of information about community palliative care available to RCH staff and the weak or non existent links made by community palliative care agencies back to the RCH. This latter perception is supported by the fact that some parent responders also described the obtaining of support, at home, from community palliative care service providers as difficult.

The situation resulting from the above, is that families are not often offered the option, by the RCH, of caring for their child at home during the latter stages of a child's illness. This situation results in families having to approach community based palliative care providers directly to state their own case, which is often difficult as the family's medical knowledge may be poor and their emotional state may be in disarray, clearly placing them at a disadvantage. In addition, practical matters such as

their geographical location, limited English language skills and problems with coping with having a profoundly ill child, may severely limit the family's ability to pursue this approach.

In order, firstly, to improve service delivery to patients and their families, secondly, to facilitate them being supported in caring for their child at home, and thirdly, to create and strengthen links between the RCH and community palliative care service providers, the development of a combined model of care between these two areas should be considered. Such a model may involve the RCH being involved in providing advice on community palliative care availability and suitability to families, developing and coordinating care plans in conjunction with the community agency involved in specific cases, and acting as a resource by advising on symptom management and paediatric issues to community palliative care agencies.

The development by the RCH of educational packages deliverable to and accessible by staff working in both the RCH and community settings will be an important factor in resourcing such a combined model of care. Many staff respondents at the RCH commented on the need for education about palliative care issues, and whilst it is beyond the scope of this research, one could postulate a similar need for education around paediatric issues in a high number of staff working in community palliative care settings.

6.1.3 Communication and care planning

Results of this investigation indicate that communication problems within the hospital, between hospital staff and families, and between the RCH and community palliative care agencies are significant. In this regard, some staff respondents stated that they thought an aid to guide them in their practice would be useful, suggesting that the development of a strategy to enhance these areas may be warranted. The key for the development of such an approach is, the author believes, to be found in Corr's 1992 task-based model of death and dying (Corr, 1992b). In this model, Corr purported that the process of dying is not confined to the patient, but rather involves all those who are drawn into the caring circle. Corr proposed the concept of a number of 'tasks' that needed to be accomplished by all those involved in the dying process for them to reach satisfactory personal and group conclusions after the child's death.

Corr's 'task' construct would seem to fit neatly with the findings of this research, in that it is clear that the term 'task', in this context, suggests an active involvement of the dying individual and those involved in his or her care. Overall, the contention of this thesis is that Corr's notion of 'tasks' is clearly congruent with the generally accepted notion of palliative care across the literature. The author believes that this research thesis has answered some of the criticism levelled at Corr's work in the past. It has done this by identifying and providing insight into many of these 'tasks' as they relate to dying children, their families and carers from a number of differing viewpoints, thus illuminating and informing the palliative care process. An interesting possibility that has begun to emerge, but will need some further research, is that some of the described 'tasks' found to be appropriate for children may *also* apply more generally to the adult population who require palliative care.

It is contended here that the development of such a tool that describes the 'tasks' of the dying process for all involved, would help solve many of the RCH internal communication problems that appear to be concentrated around palliative care issues. In addition, if such a tool were developed in conjunction with community palliative care agencies, to include those 'tasks' associated with providing care in other settings than the RCH, it would result in a very powerful communication tool that would greatly enhance the provision of palliative care to children across both in the RCH and community settings.

If, as the literature describes, the family is best served by receiving palliative care assistance across health care boundaries, the creation of such a tool as a single entity raises new problems as to where access to the tool would be sited. Because of the necessity to restrict personal medical information, some security of access will be essential. Therefore, using the child's hospital record as a portal will make access by community care providers problematic; siting the portal in the community setting will make access by other health care professionals and family inconvenient. Although it is beyond the scope of this current investigation, there clearly needs to be development of a secure but readily accessible data holding system that can receive and provide information to and from a variety of sources in various health care settings.

As previously discussed, experience by the majority of staff in both RCH and community settings, as regards to the provision of palliative care to dying children and their families is likely to be minimal, therefore merely listing or describing the 'tasks' that need to be accomplished would be of very limited value to such staff members. It follows from this that the tool must not only describe the 'what' of palliative care but must also describe the 'how'. The development of a readily accessible information resource that provides consistent accurate information on managing or accomplishing these tasks (the 'how') to all concerned, regardless of the location of the child and family, alongside the task definitions, is desirable. Such an information resource however, will need to have its content structured in several different ways to meet the needs of the different groups of individuals involved in the palliative care process. There will be considerable differences in the level of medical information provided for parents as compared to medical staff for example, and there will also be other considerations such as ethnic and religious background, level of general education and experience in handling medical equipment.

By simultaneously developing these two components, a very powerful system could be developed that provides for the input, storage retrieval and interpretation of information around specific situations for individual patients and families. At the same time, it will provide a valuable resource for health professionals as they attempt to resolve such situations in a variety of locations and family situations. By siting the information component of this system in an appropriately secure site on the internet, for example, its effectiveness can be maximised as it will be available to patients, families and health professionals in many regional settings.

6.1.4 Bereavement care and support.

Whilst there have been attempts at the RCH to provide bereavement support to families, both by individual medical consultants and social workers and more recently in a systematic way by means of the Bereavement Support Group (BSG), there has been little or no recognition that, as an institution, the RCH has a responsibility to provide bereavement care to those families who are in need. Individual medical consultants, although well meaning in their attempts to provide some follow up support to bereaved families, rarely if ever report dealing with profound grief issues. In fact, this work has indicated that most expressed concern that they were ill

equipped to deal with such issues. It is also clear that comprehensive grief counselling is beyond the resources of an already stretched social work service. In practice, it is found that most of this bereavement counselling work is seen as 'unpaid work' by those who currently perform it. In addition, since it has to be squeezed into an already busy schedule, it generally provides minimal support to bereaved families.

As stated in section 1.2.3, the BSG contacts all recently bereaved families. However, since there is no formal notification process to ensure that the BSG is made aware of the death of a child, contact does not always occur in a timely manner. In particular, deaths of children outside the RCH often involve a long notification gap, which can consequently add further distress to some families.

Because of economic and administrative restrictions, all meetings of the BSG are organised to take place at the RCH and are of a group format, and it is recognised that this may make attendance at this forum difficult for some families and family members. As an indication of the importance of this area, attendance at the BSG-facilitated annual memorial service for children in 1999 involved some 300-400 families, which would seem to indicate that the need for bereavement support is large and ongoing.

Currently, the BSG comprises a few social workers, with input from the pastoral care team, and has minimal funding provided from the social work department budget. The low profile of the BSG within the hospital is a significant area of concern. To more adequately address the needs of families in this situation, it is suggested that the RCH must recognise that the provision of bereavement care is an institutional responsibility linked to palliative care, and adopt an integrated approach to its provision by providing adequate financial support to enable proper staffing and resources for the service to function. It could be argued that a bereavement support service, set up along interdisciplinary lines with significant input from the medical and nursing disciplines as well as social work, mental health and pastoral care, would facilitate lines of referral for families, with significant grief associated issues, to community based bereavement support professionals. This would potentially have a flow-on effect by further enhancing the communication between the RCH and community based palliative care service providers.

6.1.5 Research and education.

Information obtained from respondents in this study indicated that there is a relative lack of data in the literature around areas such as symptom control and the epidemiology of life-limiting illness in paediatric palliative care. Issues dealing with bereavement and subsequent family adjustment are not well-addressed or researched, particularly in the case of bereavement of grandparents. New and innovative models of care provision need to be researched and developed for those children who may require palliative care over many years. The fact that the Australian society is a multicultural one suggests that research into how some palliative care issues may apply in other cultures may be a very important area. The inclusion of these and other emerging areas into the research activities conducted at the RCH, by staff of all disciplines, combined with the support of such research activity in a formal manner, will allow the hospital to have the opportunity to make a significant contribution to knowledge in the field of paediatric palliative care.

RCH respondents, from several disciplines, reported that obtaining formal education around palliative care issues was a difficult issue, and several stated that such education would be desirable. In previous sections of this investigation, the author has argued for the development of a multi-faceted tool that would assist in care planning and delivery to children and families requiring palliative care. Such a tool would have an information component that would serve to meet some of the acute educational needs of staff working in this area in an informal way. Whilst there are formal palliative care courses available for nursing staff through tertiary institutions, these courses to date have not had a significant paediatric component. It could be argued that the RCH is well placed to supply such a paediatric component and should establish links with tertiary education institutes to facilitate the inclusion of paediatric palliative care issues into these course structures and provide the opportunity for students to gain practical placement in this area.

Several respondents from the junior medical staff also responded that the formal inclusion of palliative care issues into the medical undergraduate curriculum would have been of great benefit to them in the workplace setting. The argument could be made that the RCH is well placed to lobby, along with other tertiary medical facilities,

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for the inclusion of palliative care issues into the undergraduate medical curriculum. Another argument could be made for the development, at a senior medical level, within the RCH of a consultant position in palliative care. This position then may be seen by other medical personnel both within the RCH and the community setting as formal recognition that children and their families have special needs in this area. As the research shows, general paediatricians at the RCH estimated their involvement with palliative care issues to be in fewer than five patients per year. It is therefore likely that, just as their nursing counterparts, they lack appropriate experience, particularly at the junior level. Community-based paediatricians would have even less involvement with palliative care issues due to the extremely small numbers of children dying in the community setting. Thus the creation of a RCH Palliative Care Consultant position could serve as a resource to community and hospital senior medical professionals, and potentially lead to an improvement in the dialogue between the RCH and community based paediatricians around palliative care issues.

To take this argument to its logical conclusion the aforementioned consultant position should be seen as part of a team approach to resourcing the staff of the RCH in providing palliative care. The author would argue for the establishment of a team consisting of a consultant medical officer, a senior nurse consultant and a social worker, all, having suitable past experience and or qualifications in the pediatric palliative care sphere. Such a team would provide a broad view of each individual child and family's situation and could act as a resource for both hospital and community based staff advising the 'home' unit on all aspects of the care of dying children and their families and assisting in the co-ordination of care between the hospital and community sectors. In addition this team would be well placed to raise the profile of pediatric palliative care in state, national and international forums on child care in general.

6.2 Limitations of this research

Whilst the author has made broad statements as to the applicability of this research to the provision of pediatric palliative care specifically, and palliative care for adults more generally, it must be acknowledged that this research has limitations. This research could be criticised for its narrow focus, in that the perspectives reported herein and the conclusions that flow from them are all, in theory, open to bias as in

essence this could be seen as a single institute study. In general, applying findings from such studies to the wider setting should be done cautiously. In practice, whilst it is true that respondents from the parent group were all patients of the RCH, and their care was driven by staff from the RCH, some of these patients and families received care and support during their child's illness from other paediatric institutions and community based programmes. Similarly, some staff respondents from the medical group in particular, may have held appointments at other paediatric care facilities and may have confronted the issues discussed in this research in those other institutions. The author feels that this 'cross fertilisation' of experience with other institutions and care providers, although not addressed in this research, may help to negate any problems with bias that may result from this research being performed at a single institution.

In addition, the literature abounds with reports of the stresses involved for all involved with the palliative care process. For reasons of their own, respondents may have withheld information that was relevant to the subject or have consciously imparted their own bias to the retelling of their story. In addition, some degree of unconscious bias is expected with the retelling of events of this significance in the lives of the respondents. Such bias in the retelling, would have the end result of biasing the subsequent findings in some way. There is also the possiblity, as Baruch (1981) has detailed, of some parent respondents using this research investigation to debrief in some way about the death of their child. Whilst the author was careful in the parent respondent selection, and indeed several potential parental respondents were eliminated because they seemed 'too eager' to participate, the possibility exists that parent respondents had hidden motives in participating in this research. RCH staff too may have voluntarily withheld information from the author, or biased information, when participating in this research. Again, such actions would have had the effect of biasing the findings in some way. The author feels that, having extensively presented the findings of this research to practitioners of pediatric palliative care in settings other than the RCH, and receiving affirmation that they had similar experiences and could relate strongly to this body of work, the effect of hidden bias in this work appears to be minimal.

Lastly, it could be said that the applicability of this work to the wider setting is compromised as the parental respondent group is not representative of the multicultural nature of Australian society in that parental respondents are all from a European background. They are from established Australian caucasian families (although this is not detailed in the findings), there are no Australian Aboriginal parental respondents, nor are there any first generation migrant families who participated in this research, although the cohort of patients who had died in the study period did indeed have children from such families. Aboriginal families have a differing perception of the notion of family, death and the notion of health care from that of the Australian population as a whole, and there is much published research to this effect (Lake 1992; Anderson 1994). First generation migrant families could be expected to have much stronger links with their own native cultural perceptions of illness, death and health care than subsequent generations who had grown up in Australia. The omission of parental participants from cultural backgrounds other than the Australian one could be seen as a limiting factor in the applicability of this research into the wider setting.

6.3 Conclusion

Despite advances in medical knowledge and the provision of health care, children continue to die, albeit in smaller and smaller numbers. The premature death of a child is seen as a disruption to human development, and is perceived as less acceptable than that of the expected death that will come to us all as a result of ageing. Families are confronted with many crises from the time of their child's diagnosis with a potentially fatal illness, and the pain of anguish and loss does not end with the death of the child but may take many years to be incorporated into the fabric of the family's life.

It has often been asked of me how I can work in such an emotionally demanding and charged field, and my response has always been that I enjoy the work and find it rewarding, a privilege and always a challenge. However I have been witness over the years to the distress of others, both parents and health professionals when confronted with the prospect of caring for a dying child. The process of providing palliative care affects all those who are drawn into it; child, parents, extended family and the various disciplines of health-care providers. In undertaking this research I hoped to focus on what is needed to participate in the palliative care process, not only from the

perspective of a nurse (which is my professional background), but from the multiple perspectives just described, and to provide a framework that allowed for the best possible outcomes for all involved.

I hope that readers of this work who are involved in providing palliative care for dying children and their families can use the themes presented to help inform their own actions and interactions. Furthermore it is to be hoped that those charged with the responsibility of managing institutions where palliative care for children is practised, can utilise recommendations from this thesis to improve the provision of palliative care to dying children and their families.

Addendum

Since the original draft of this thesis was submitted for examination in 2001 there has been major changes to the practice of paediatric palliative care in Victoria. In 2000 the RCH submitted an application for Government funding to establish a palliative care service, based in part on the recommendations from this research. The Victorian State Government subsequently, in 2001, approved recurrent funding for the establishment of the Victorian Pediatric Palliative Care Program (VPPCP), a statewide consultative palliative care service across three campuses, RCH, Monash Medical Centre and Very Special Kids Inc. The VPPCP comprises Medical, Nursing and Social Work staff. To date the VPPCP has been involved in 430 cases of children requiring palliative care across Victoria.

In addition the RCH and the VPPCP in partnership undertook the development of an extensive web based resource on paediatric palliative care, this website, www.rch.org.au/palliative care, went live in 2002. Information on the website is structured in two ways, one orientated towards health professionals, the other orientated towards usage by families. To date the website has recorded 16,659 'hits' seeking to view 67,062 pages of data, currently the website averages 47 hits/day, viewing 188 pages of data/day. 39% of persons who access the site are health professionals, 13% are families, the remainder are unidentified. 30% of hits have come from Australia, 26% from the USA, 17% from the United Kingdom and 5% from Canada.

In 2003 the RCH in conjunction with the University of Melbourne, offered a subject unit in paediatric palliative care, within its Postgraduate Diploma in Palliative Care Nursing, the course is in its second year of operation.

Commencing in 2002 the Australian Federal Government, Department of Health and Ageing undertook, at a national level, similar research to this thesis. The final report of this project, 'Paediatric Palliative Care Service Model Review' was published in 2004 its findings were congruent to those described in this research, and it made recommendations that were similar to those made by the author in this thesis.

References

Agan, D. (1987). Intuitive knowing as a dimension of nursing. *Advances in Nursing Science,* 10, (1), 63-70.

Anderson, I. (1994). Ethics and health research in Aboriginal communities. In *Conference Papers, Researching Health Care: Methods, Ethics and Responsibility.* Melbourne, St. Vincent's Hospital.

Anthony, S. (1972). *The discovery of death in childhood.* New York: Basic Books.

Aranda, S. (1999). Global perspectives on palliative care. *Cancer Nursing,* 22, 33-39

Ashby, M.A., Kosky, R.J., Laver, H.T. (1991). An enquiry into death and dying at the Adelaide Children's hospital: a useful model? *Medical Journal of Australia,* (154),165-170.

Australian Assoc. for Hospice and Palliative Care. (1995). Directory of Hospice and Palliative Care Services Australia. Perth: Author

Baruch, G. (1981). Moral Tales: parent's stories of encounters with the health professions. *Sociology of Health and Illness,* (3), 275-295.

Blauner, R. (1966) Death and Structure. *Psychiatry,* 29, 378-394

Bluebond- Langer, M. (1978). *The private worlds of dying children.* Princeton: Princeton University Press.

Bowlby, J. (1975). *Attachment and Loss, Vol II. Separation: anxiety and anger.* Middlesex: Penguin Books.

Bosanquet, N., Salisbury, C. (1999). *Providing a Palliative Care Service. Towards an Evidence Base.* London: Oxford University Press.

Burgess, R.G. (1984). *In the Field: An Introduction to Field Research.* London: Allen & Unwin.

Burne, S.R., Dominica, F., Baum, J.D. (1984). Helen House-a hospice for children: Analysis of the first year. *British Medical Journal,* (289), 1665-1668.

Campbell, D.A., Pierce, R.J. (1998). Long-term ventilatory support at home: any progress? [Editorial]. *Medical Journal of Australia,* (168), 7-8.

Carr-Gregg, M.R.C., Sawyer, S.M., Clarke, C.F., Bowes, G. (1997) Caring for the terminally ill adolescent. *Medical Journal of Australia,* (166), 255-258.

Chambers, E.J., Oakhill,A., Cornish, J.M., Curnick, S.(1989). Terminal care at home for children with cancer. *British Medical Journal,* (298), 937-940.

Chambers, E.J., Oakhill, A. (1995). Models of care for children dying of malignant disease. *Palliative Medicine*, (9,) 181-185.

Chambers, T.L. (1987) Hospices for children? *British Medical Journal*, (294), 1309-1310.

Childers, P., Wimmer, M. (1971). The concept of death in early childhood. *Childhood Development*, 42, 1299-1301.

Collins, J., Stevens, M.M., Cousens, P. (1994). *Home care for the dying child: the parent's perception*. Project for the Oncology Unit, Royal Alexandra Hospital for Children, Sydney.

Consultative Council on Obstetric and Paediatric Mortality and Morbidity. (1999). Annual report for the year 1997, incorporating the 36th Survey of perinatal deaths in Victoria. Melbourne: Author

Copp, G. (1996). *Facing impending death: the experiences of patients and their nurses in a hospice setting.* [PhD thesis.] Oxford: Oxford Brookes University

Copp, G. (1997). Patients and nurses constructions of death and dying in a hospice setting. *Journal of Cancer Nursing*, 1(1), 2-15

Corr, C.A, Corr, D.M. (1985a). Paediatric hospice care. *Pediatrics*, (76), 774-780.

Corr, C.A., Corr, D.M. (1985b). Situations involving children: A Challenge for the Hospice Movement *The Hospice Journal*, Vol 1 (2), 63-77.

Corr C.A., Corr D.M. (1992). Children's Hospice Care. *Death Studies,* (16), 431-449.

Corr, C. (1992). A task based approach to coping with dying. *Omega*, 24(2), 81-94.

Darbyshire, P., Haller, A., Fleming, S. (1997). *The Interstellar cold: parent's experiences of their child's palliative care*. A report prepared for the South Australian Health Commission, Palliative Care Program, statewide projects.

Davis, B. (1996) Caring for dying children: Nurses' Experiences. *Paediatric Nursing*, Vol 22 (6), 500-507.

De Veber, L L. (1993). Physiological differences between children and adults that affect physical findings and symptom development. In, D. Doyle, G.W. Hanks & N. MacDonald. (eds.) *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press.

Denzin, N. (1989). *The research act: A Theoretical Introduction to Sociological Methods*. New Jersey: Prentice Hall.

Deeley, L., Stallard, P., Lewis, M., Lenton, S. (1998). Palliative care services for children must adopt a family centred approach. [Letter], *British Medical Journal*, (317), 284.

Dent, A., Condon, L., Blair, P., Fleming, P. (1996) A study of bereavement care after a sudden and unexpected death. *Archives of Diseases of Childhood*, (74), 522 – 526.

Dent, H.S. (1990). Pre-registration house officers in the four Thames regions: Survey of education and workload. *British Medical Journal*, (300), 713-715.

Diamond, N. (1982). Cognitive theory. In B.B. Woolman (ed.), *Handbook of Developmental Psychology*. New Jersey: Prentice-Hall.

Doyle, D., Hanks, G., Mac Donald, N. (1993).(eds) *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press.

Eakes, G. (1984). Grief resolution in hospice nurses. *Nursing and Health Care*, Vol 1 (5), 243-248

Erikson, E.H. (1963). *Childhood and society*. New York: Norton

Farrell, M. (1996). The role of a children's hospice. *Paediatric nursing*, (8), 6-8.

Farrow, G. (1981). Helen House: Our First Hospice for Children. *Nursing Times*, (77), 1433-1434.

Finlay, I., McQuillan, R. (1995). Paediatric palliative care: the role of an adult palliative care service. *Palliative Medicine*, (9), 166-167.

Flavell, J.H. (1963). *The developmental psychology of Jean Piaget*. New York: Van Nostrand Publishing

Fleischman, A.R. (1994). Caring for gravely ill children. *Pediatrics*, (94), 433-439.

Fleischman, A.R. (1998). Commentary: Ethical issues in paediatric pain management and terminal sedation. *Journal of Pain and Symptom Management*, (15), 260-261.

Frager, G. (1996) Paediatric palliative care: building the model, bridging the gaps. *Journal of Palliative Care*,(12), 9-12.

Frager, G. (1997). Palliative care and terminal care of children. *Child and Adolescent Psychiatric Clinics of North America*,(6), 889-909.

Freud, S. (1964). *An Outline of Psychoanalysis*. London: Hogarth Press

Frydenberg, E., Lewis, R. (1991). Adolescent coping the different ways in which boys and girls cope. *Journal of Adolescence*, (14),119-133.

Fulton, R. (1972). Death and Dying: Some sociological aspects of terminal care. *Modern Medicine*, May (29), 74-77

Glaser, B.G., Strauss, A.L. (1965a). *Awareness of dying*. Chicago: Aldine Publishing.

Glaser, B.G., Strauss, A.L. (1965b). Temporal aspects of dying as a non scheduled status passage. *American Journal of Sociology*, (71), 48-59.

Glaser, B.G., Strauss, A. L. (1967). *The Discovery of Grounded Theory: a strategy for qualitative research*. Chicago: Aldine Publishing.

Glaser, B.G., Strauss, A. L. (1968). *Time for Dying*. Chicago: Aldine Publishing.

Glaser, B.G. (1972). *Basics of Grounded Theory analysis*. Mill Valley: Sociology Press.

Goldman, A., Neardsmore, S., Hunt, J. (1990). Palliative care for children with cancer – home, hospital or hospice? *Archives of Disease of Childhood*, (65), 641- 643.

Goldman, A. (1995). Palliative care for children [editorial]. *Palliative Medicine*, (9), 179-180.

Goldman, A. (1998). ABC of palliative care: special problems of children. *British Medical Journal*, (316), 49-52.

Guba, E., Lincoln, Y. S. (1981.) *Naturalistic Inquiry*. Beverly Hills: Sage Publishing.

Hain, R.D.W., Patel, N., Crabtree, S., Pinkerton, R.(1995). Respiratory symptoms in children dying from malignant disease. *Palliative Medicine*, (9), 201-206.

Health Department Victoria. (1991). *Caring for people with Terminal illness. A manual outlining Victorian palliative care standards and guidelines*. Melbourne: Author.

Hilton, T., Orr, R.D., Perkin, R.M., Ashwal, S. (1993). End of life care in Duchenne muscular dystrophy. *Pediatric Neurology*; (9), 165-177.

Hunt, A.M. (1990). A survey of signs, symptoms and symptom control in 30 terminally ill children. *Developments in Medicine, Child Neurolology*, (32), 341-346.

Hunt, A., Burne, R. (1995). Medical and nursing problems of children with neurodegenerative disease. *Palliative Medicine*, (9), 19-26.

International Work group on Death, Dying and Bereavement, Work group on Palliative Care for Children. (1993). Palliative care for children. *Death studies*, (17) 277-280.

Jacobsen, S. J., Koren, G. (1993). Pharmacology of symptom control in children. In D. Doyle, G.W. Hanks & N. MacDonald (eds). *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press.

James, J.A., Harris, D.J., Mott, M.G., Oakhill, A. (1988). Paediatric oncology information pack for GPs. *British Medical Journal*, (296), 97-98.

Jankovich, M, (1989). Meetings with parents after the death of their child from leukaemia. *Paediatric Haematology & Oncology*, (6), 155-160.

Jefidoff, A., Gasner, R. (1993). Helping the parents of dying children: an Israeli experience. *Journal of Paediatric Nursing*, (8), 413-415.

Jurk, I. H., Ekert, H., Jones, H J. (1981). Family responses and mechanisms of adjustment following death of children with cancer. *Australian Paediatric Journal*, (17), 85-88.

Kellehear, A. (1990). *Dying of Cancer: the final year of life*. London: Harwood Academic Publishers.

Kelly, A. F., Hewson, P. H. (2000). Factors associated with recurrent hospitalisation in chronically ill children and adolescents. *Journal of Paediatrics and Child Health*; (36), 13-18.

Klaus, M.H., Kennel, J.H. (1976). Maternal-infant bonding. St Louis: Mosby.

Krause, D. (1976). Children's concepts of death. In I.M. Martinson (ed.) *Home care for the dying child: professional and family perspective*. New York: Appleton-Century-Crofts.

Kubler-Ross, E. (1969). *On Death and Dying*. New York: Macmillan Press.

Kohler, J. A., Radford, M. (1985). Terminal care for children dying of cancer: quantity and quality of life. *British Medical Journal*, (291), 115-116.

Lake,P. (1992). A decade of Aboriginal health research. *Aboriginal Health Information Bulletin*, (17), 12-16.

Landsdown, R., Benjamin, G. (1985). The development of the concept of death in children aged 5-9. *Child Care Health Developments*, (11), 13-20.

Lattanzi, M.E. (1985). An approach to caring: Caregiver concerns. In, C.A. Corr. & D.M. Corr (eds.) *Hospice approaches to paediatric care*. New York: Springer press.

Lattanzi- Licht, M.E. (1991.) Professional stress: Creating a context for caring. In, D. Papadatou & C. Papadatos (eds) *Children and Death*. Washington D C. Hemisphere press.

Lauer, M.E., Camitta, B.M. (1980). Home care for dying children: a nursing model. *Journal of Pediatrics*, (97), 1032-1035.

Lauer, M. E., Mulhern, R.K., Wallskog, J.M., Camitta, B.M. (1983). A comparison study of parental adaptation following a child's death at home or in hospital *Pediatrics*,(71), 107-112.

Lauer, M. E., Mulhern, R. K. (1984). Home care referral: parental self-selection versus psychosocial predictors of capacity. *American Journal of Hospice Care*; (1), 35-38

Lauer, M.E., Mulhern, R.K., Hoffman, R.G.,Camitta, B.M. (1986). Utilization of hospice/ home care in pediatric oncology. A national survey. *Cancer Nursing*, (9), 102-107.

Lauer, M.E., Mulhern, R.K., Schell, M.J., Camitta, B.M. (1989). Long-term follow-up of parental adjustment following a child's death at home or hospital. *Cancer*, (63), 988-994.

Lauer, M E. (1997) Ongoing challenges in pediatric hospice care. *Acta Paediatrics* (86), 1037-1039.

Liebke, K. (1999.) In *Conference Proceedings, 5th Australian Palliative Care Conference.1990.* Canberra: Palliative Care Australia.

Lucco, A. (1991). Assessment of the school age child. *Families in Society*, 72, 394-408.

Mastroyannopoulou, K., Stallard, P., Lewis, M., Lenton, S. (1997). The impact of childhood non-malignant life-threatening illness on parents: gender differences and predictors of parental adjustment. *Journal of Child Psychology & Psychiatry*, (38) 823-829.

McDougall, P., Rogers, J., van Doorn, H., Loughnan, M. (2000). The Death of a Child and Sudden Infant Death. In, J.Smart, T.Nolan.(eds.) *Paediatric Handbook.* Blackwell Science (Asia).

McGrath, P. J.,Craig, K.D. (1989). Developmental and psychological factors in children's pain. *Paediatric Clinics of North America*, (36), 823-835.

McKeogh, M. M., Evans, J. A. (1996). Paediatric palliative care: the role of an adult palliative care service [Letter].*Palliative Medicine*, (10), 51.

McQuillan, R., Finlay, I. (1996). Facilitating the care of terminally ill children. *Journal of Pain and Symptom Management*, (12) 320-324.

Meehan, J. (1999). *Cystic fibrosis: terminal care in a paediatric and adolescent population.* Paper presented at the Australian Cystic Fibrosis Association, Annual Meeting 1999, Sydney.

Meleis, A., Schultz, P. (1988). Nursing epistemology: Traditions, Insights, Questions. *Image : Journal of Nursing Scholarship*, 20, (4) 217-221.

Minichiello, M., Aroni, A., Timewell, E., Alexander L. (1995). *In –depth interviewing: Principles, Techniques, Analysis.* (2nd Ed). Melbourne: Longman Cheshire publishing.

Morgan, E. R., Murphy, S. B. (2000). Care of children who are dying of cancer. *New England Journal of Medicine,* (342) 347-348.

Mulhern, R. K., Crisco, J, J., Camitta, B. M. (1981). Patterns of communication among pediatric patients with leukemia, parents and physicians: prognostic disagreements and misunderstandings. *Journal of Pediatrics,* (99) 480-483.

Mulhern, R. K., Lauer, M. E., Hoffman, R. G. (1983.) Death of a child at home or in The hospital: subsequent psychological adjustment of the family. *Pediatrics,* (71) 743-747.

Munhall, P., Oiler-Boyd, C. (1993). *Nursing Research: A qualitative perspective.* New York: National League for Nursing Press.

Munhall, P. (1994). *Revisioning phenomenology: Nursing and health science research.* New York: National League for Nursing Press.

Nagy, M. (1948). The child's theory concerning death. *Journal of Genetics and Psychology,* 73, 3-27.

Nagy, S. (1996). Psychological growth and development: birth to18 months. In A. Adams, C. McQuellin, S. Nagy (eds) *Nursing the Infant, Child and Adolescent. Interactions and Care. Vol 1.* Sydney, MacLennan & Petty.

Newman, M.A. (1992). Prevailing paradigms in nursing. *Nursing Outlook* 40: (1) 10-13.

Newton, R.W., Bergin, B., Knowles, D. (1986). Parents interviewed after their child's death. *Archives of Diseases of Childhood,* (61), 711-715.

Norman, R., Bennett, M. (1986.) Care of the dying child at home: a unique co-operative relationship. *Journal of Advanced Nursing,* (3) 3-16.

Palliative Care Australia. (1998). *The State of the Nation 1998.* Report of National Census of Palliative Care Services. Canberra: Author.

Palliative Care Australia. (1999). *Standards for Palliative Care Provision.* 3rd edition. Canberra. Author.

Papadatou, D. (1991). Working with dying children: A professionals personal journey. In D. Papadatou & C.Papadatos (eds) *Children and Death.* Washington: Hemisphere Press.

Parker, D., Maddocks, I., Stern, L. M. (1999). The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy. *Journal of Paediatrics & Child Health,* (35) 245-250.

Parse, R. (1987). *Nursing Science: Major Paradigms, Theories and Critiques*. London: W.B. Saunders & Co.

Pattison, E. M. (1977). *The Experience of Dying*. New York: Simon & Schuster.

Pettle, M. S. A., Lansdown, R. G. (1986). Adjustment to the death of a sibling. *Archives of Diseases of Childhood*,(61), 278-283.

Piaget, J. (1954). *The construction of reality in the child*. New York: Basic Books.

Potter, J.F. (1982). A Challenge for the Hospice movement *New England Journal of Medicine*, (302), 53-55.

Quint, J.C. (1967). *The nurse and the dying patient*. New York: Macmillan.

Rainey, L. (1988). The experience of dying. In, H. Wass, F. Berardo, & R. Neymeyer (eds) *Dying: facing the Facts* (2nd ed. pp 137-157) Washington: Hemisphere press.

Rando, T A. (1983). An investigation of grief and adaptation in parents whose children have died from cancer. *Journal of Pediatric Psychology*, (8), 3-19.

Raphael, B. (1983). *The anatomy of bereavement*. New York: Basic Books.

Robinson, W. M., Ravilly, S., Berde, C., Wohl ,M. E.(1997). End-of-life care in cystic fibrosis. *Pediatrics*, (100), 205-209.

Rogers, J. (1994). Lymphoma-a personal experience. *Medical Journal of Australia*, (161), 713-715.

Royal Children's Hospital, Brisbane (1999). *A Practical Guide to Pediatric Oncology Palliative Care*. Brisbane : Author.

Royal Children's Hospital, Melbourne. (2000) *Policy and Procedure manual*. Melbourne : Author.

Royal College of Paediatrics and Child Health. (1997). *A Guide to the Development of Children's Palliative Care Services*. 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. London: Author.

Sach, S. (1997). When a child dies. Caring for children with life-threatening conditions. *Palliative care service development series*. Department of Human Services. Melbourne: Government Printing Office.

Sandelowski, M. (1986). The problem of rigour in qualitative research. *Advances in Nursing Science*, 8 (3), 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigour in qualitative research revisited. *Advances in Nursing Science*, 16 (2),1-8.

Sawyer, S. M. (2000). She smiles. In, A. Kellehear (ed.), *Australian stories: Grief and Remembering*. Melbourne: Rivoli.

Sirkia, K., Saarinen, U. M., Ahlgren, B., Hovi, L. (1997). Terminal care of the child with cancer at home. *Acta Paediatr*ics, (86), 1125-30.

Sirkia, K., Hovi, L., Pouttu, J., Saarinen-Pihkala, U. M. (1998). Pain medication During terminal care of children with cancer. *Journal of Pain and Symptom Management*, (15), 220-226.

Sloper, P. (1996). Needs and responses of parents following the diagnosis of childhood cancer. *Child: Care, Health, Development*, (22), 187-202.

Stallard, P., Mastroyannopoulou, K., Lewis, M., Lenton, S. (1997). The siblings of children with life-threatening conditions. *Child Psychology Psychiatric Review*, (2), 26-33.

Stoddard, S. (1979) *The Hospice Movement*. London: Jonathon Cape

Stein, A., Forrest, G. C., Woolley, H., Baum, J. D. (1989). Life-threatening illness and hospice care. *Archives of Diseases of Childhood*, (64), 697-702.

Stein, A., Woolley, H. (1990). An evaluation of hospice care for children. In, J.D. Baum, F. Dominica, R.N. Woodward.(eds) *Listen my child has a lot of living to do*. London: Oxford University Press.

Stein, A., Woolley, H. (1994). Caring for the carers. In, A. Goldman.(ed) *The Care of the Dying Child*. London: Oxford University Press.

Stevens, D., Owen, M. (1987). Hospices for children? [Letter]. *British Medical Journal*; (294) 1548.

Stevens, M. (1993). Family adjustment and support. In D. Doyle, G. Hanks, N. Mac Donald. (Eds). *The Oxford Textbook of Palliative Medicine*. New York: Oxford University Press.

Strauss, A. Corbin, J. (1990*). Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park: Sage.

Streubert, H., Carpenter, D. (1995). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott Press.

Sudnow, D. (1967). *Passing On*. New Jersey: Prentice-Hall.

Tonkins, S.A.M., Lambert, M. J. (1996). A treatment outcome study of bereavement groups for children. *Child and Adolescent Social Work Journal*, (13) 3-21

Vachon, M.L.S. (1987). *Occupational stress in the care of the critically ill, the dying and the bereaved.* New York: Hemisphere Publishing.

Very Special Kids Incorporated. (2000). *Very Special Kids* [Pamphlet]. Melbourne: Author.

Vickers, J L., Carlisle, C. (2000). Choices and control: parental experiences in paediatric terminal home care. *Journal of Paediatric Oncology Nursing,* (17) 12-21.

Victorian State Government. (1997). Victorian Palliative Care Service Integration. *Directions for the future.* [Report to the Minister for Aged Care]: Palliative Care Implementation Steering Committee. Melbourne: Government Printing Office.

Wadsworth, Y. (1984). *Do it yourself research.* Collingwood: Victorian Council of Social Services.

Waechter, E. (1971). Childrens' awareness of fatal illness. *American Journal of Nursing,* (71) 1168-1172.

Wallace, A C., Jackson, S. (1995). Establishing a district palliative care team for children. *Child: Care, Health & Development,* (21) 383-385.

Warren, W.G., Chopra P N. (1979). An Australian survey of attitudes to death. *Australian Journal of Social Issues,* 14, 2, 134-142.

Whittam, E. H. (1993). Terminal care of the dying child. Psychosocial implications of care. *Cancer;* (71) 3450-3462.

Wheeler, P., Foerster-Lange, N. (1985). Improving Care for Hospitalized Terminally ill Children: A Practical Model. In, C.A. Corr & D.M. Corr (eds). *Hospice approaches to Paediatric care.* New York: Springer Publishing.

Wilkinson, S. (1988). *The child's world of illness: the development of health and illness behaviour.* Cambridge: Cambridge University Press.

Williams, H. (1963). On a teaching hospital's responsibility to counsel parents concerning their child's death. *Medical Journal of Australia,* (16) 643-645.

Wilson,D (1985). Developing a hospice programme for children. In, C.A. Corr & D.M. Corr (eds) *Hospice approaches to paediatric care.* New York: Springer Publishing.

Wilson, D. C. (1988). The ultimate loss: the dying child. *Loss, Grief, Care,* (2) 125-130.

Wolfe, J., Grier, H. E., Klar, N. (2000). Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine,* (342) 326-333.

Women's and Children's Health, Melbourne. (2001). Annual Report 2000/2001 Carlton: Author.

Woolley, H., Stein, A., Forrest, G. C., Baum, J. D. (1991). Cornerstone care for Families of children with life-threatening illness. *Developments in Medicine, Child Neurology*, (33) 216-224.

Woolley, H., Stein, A., Forrest, G. C., Baum, J. D. (1989a). Imparting the diagnosis of life threatening illness in children. *British Medical Journal*, (298) 1623-1626.

Woolley, H., Stein, A., Forrest, G. C., Baum, J. D. (1989b). Staff stress and job satisfaction at a children's hospice. *Archives of Diseases of Childhood*, (64) 114-118.

World Health Organization. (1998). *Cancer Pain and Palliative Care in Children.* [Monograph] Geneva: Author.

Appendix 1. Information sheet to parents

" An Analysis of Paediatric Palliative Care in the state of Victoria"

To the ....family.

I am inviting you to participate in the study " **An Analysis of Paediatric Palliative Care in the state of Victoria"**
which is being undertaken as my Master of Health Sciences at the Victorian University of Technology. I have worked in the Oncology Unit at Royal Children's Hospital for over twenty years and during that time have cared for many dying children, and their families.

With this study I hope to obtain a picture of patient, family and staff needs during the process of delivering palliative care to children, with the emphasis on keeping them at home for as long a time as possible. And to contrast this with another picture of currently available resources and facilities in the community, thus highlighting areas that need improving and the resources required to provide the best palliative care for children and families in the terminal phase of an illness.
Participation in this study is voluntary. The study would require you and your children to be interviewed as a family about your child's care during the terminal phase of his/her illness. The interview will be of approximately one hours duration and you may be asked to take part in a shorter second interview to clarify your information. As a family you would decide where and when the interview would take place.

All interviews will be audio tape recorded, unless you have a strong objection. Recording the interviews gives the interviewer a complete record of the interview for later study, in addition it allows the interviewer to give full attention to you and your answers without having to take interview notes. The taped interviews will be transcribed for analysis. Both the tapes and the transcriptions will not have your name on them, instead, these will be coded to protect your identity. **Only the researcher and his supervisor will ever listen to the tapes or read the transcripts**, which will be kept under strict conditions of security for five years and then destroyed. Further, when writing the thesis and other reports and or publications no real names or any other identifying information will be used.

While it is not intended that this interview be an uncomfortable experience, it is understood that you could experience some discomfort and distress recalling the events surrounding your child's death,. **Should you feel that you would like to stop at any point please say so.** If you feel that you need professional help for your distress then the interviewer can arrange an appropriate referral.

You can retrieve any material that you have provided, or you can request copies of transcripts and audio tapes at any stage.

You can withdraw from the study at any time without any compromise to access and care at the Royal Children's Hospital.

If at any stage during the research you have concerns regarding the research then please feel free to contact the secretary of the Ethics in Human Research Committees at either the Royal Children's Hospital on Ph.9345 5044, or The Victoria University of Technology at P.O.Box 14428 MMC Melb. 3000.

I shall contact you in two weeks to see if you are willing to participate in this study. If you have further questions please do not hesitate to contact me at the numbers below.

Researcher   David Sutton   Ph (03)9345 5645 (Bus)   Fax (03) 9345 6576
                                Email: suttond @ cryptic.rch.unimelb.edu.au

Appendix 2. Consent form

I...
....

consent to take part in the research study :

"AN ANALYSIS OF PAEDIATRIC PALLIATIVE CARE IN THE STATE OF VICTORIA"

being conducted at Victoria University of Technology and the Royal Children's Hospital by

DAVID SUTTON

I further consent being the guardian/mother/father of
....
....
to him /her/them taking part in the same study.

I/we certify that the objectives of the study, together with any risks to me/us associated with my/our participation, have been fully explained to me/us in writing in a plain language statement (copy attached) . I understand that I/we am/are free to withdraw from the study at any time without explanation, and that non-participation will not in any way affect access to the best available treatment and care at the Royal Children's Hospital or jeopardise me/us in any other way.
I/we understand that I /we will be required to participate in an interview about our child's palliative care during the terminal phase of his/her illness, and that this interview will be audio recorded.
I/we have been informed that confidentiality for all information I/we provide will be safeguarded and that anonymity is guaranteed.
I/we understand that the material I/we provide will be incorporated into a Masters Thesis and that portions may be used for presentation at conferences and seminars. In addition I understand that this material may be used by the Royal Children's Hospital as part of a submission to the government for funding for a Palliative Care Service.

Signed.............................   Date........................

Witness............................   Name....................

Relationship...........................   Date....................

Any queries or complaints about your participation in this project may be directed to the researcher, or the Sectretaries
        Ethics in Human Research Committee, Royal Children's Hospital Parkville

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Melb. 3052
Human Research Ethics Committee, Victoria University of Technology P.O.
Box 14428 MMC Melb. 3000
Researcher: David Sutton Ph (03) 93455645 Bus

Appendix 3. Focus group / Interview guide

Interview guide (Staff)

1/ How many children in your care have required "palliative care" in the last 12 months?
How were those children identified?
Was the transition clear?

2/ How was this information communicated to the child and their family?
What do you feel are the most important factors in communication in this setting?
Are there any aspects of this that further training may help you with?

3/ What services from within the hospital were engaged in the palliative care of your
patients?
- social work
- psychiatry
- pastoral care
- pain team
- other.

What were the referral criteria for individual patients?
What was your perception of the availability/efficacy of involved services?

4/ Were any community services involved in the care of these patients?
- RDNS or other domiciliary nursing
- Adult palliative care teams
- GP
- Parent support groups
- Other

What was your perception of their availability/efficacy?
What were the referral criteria? How were services engaged and coordinated?

5/ In your experience, have all members of your team shared similar views regarding the
care of dying children? How is conflict managed within the team? Who makes the major
decisions regarding palliative care?

6/ Would more patients be suitable for care at home if supports were available. What
would be needed?

7/ How are family wishes regarding the death of their child currently communicated
and/or documented? Could this be improved and, if so, how?

8/ What hospital supports are available to staff who experience distress during or after the
terminal phase of child's illness? What is your impression of their availability and
efficacy?

9/ What do you perceive are the barriers to the provision of effective palliative care at the RCH?
How can these be overcome?

10/ Do you have an approach to the follow-up of bereaved families? Is this an individual approach or departmental policy?

11/ Would it help you to have access to expertise in paediatric palliative care? How would you anticipate using this?

12/ Have you or your unit undertaken any research in this area?

Appendix 4

PALLIATIVE CARE SURVEY

Mark on line provided .

1/ Current communication and documentation procedures regarding the palliative care of patients is;

poor   excellent

|___|___|___|___|___|___|___|___|___|___|___|

2/ The interface between the RCH and community agencies as regards palliative care is;

poor   excellent

|___|___|___|___|___|___|___|___|___|___|___|

3/ My personal knowledge of the services available for palliative care patients is;

inadequate   adequate

|___|___|___|___|___|___|___|___|___|___|___|

4/ Coordination of services for patients with palliative care needs within the RCH is;

poor   excellent

|___|___|___|___|___|___|___|___|___|___|___|

5/ My knowledge of bereavement care and services available to bereaved families is

poor   excellent

|___|___|___|___|___|___|___|___|___|___|___|

6/ Utilisation of nursing and allied health staff in discussions with families is;

poor   excellent

|__|__|__|__|__|__|__|__|__|__|__|

7/ Financial assistance and practical supports (eg. Respite) for palliative care patients is;

poor   excellent

|__|__|__|__|__|__|__|__|__|__|__|

8/ Facilities for the care of children and their families at the time of death are;

poor   excellent

|__|__|__|__|__|__|__|__|__|__|__|

9/ Ethical and legal support for difficult decision-making and conflict resolution is;

poor   excellent

|__|__|__|__|__|__|__|__|__|__|

Name(optional)

Position

Discipline