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Perceptions of Life and Death in Paediatric Palliative Care

*Family Communication about the End of Life*

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1169052, Health Psychology

Date of enrolment in the programme: 1 February, 2009 Expected date of completion: 1 July, 2012

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Co-Supervisor: Roderick MacLeod

Advisors: Starship PPC Team, Andrew Thompson

*A thesis submitted in fulfilment of the requirements for the degree of Doctorate of Philosophy in Health Psychology, The University of Auckland, 2012.*
Abstract

Introduction: Talking about death is not a simple task, especially when children are involved. Qualitative studies of patients and families involved in Paediatric Palliative Care (PPC) explore themes relating to perceptions of death, communication around it, and support during the process. A quantitative study seeks to compare caregivers’ assumptions of what their children believe about death as a biological concept to what the children report believing. We aim to increase caregivers’ knowledge about communicating with children at and about the end of life.

Methods: (1.) A quantitative study (n=141) compared healthy children’s death understanding interview answers to those predicted by their caregivers. (2.) Nineteen caregivers of PPC patients were interviewed regarding communicating prognosis with their children. (3.) Sixteen PPC patients and siblings recorded daily thoughts in diaries for one to four weeks. (4.) Eighteen siblings of PPC patients were interviewed about their roles during their siblings’ lives and the support they received during the process. All qualitative data were analysed thematically to gain families’ perspectives about communicating in relation to PPC.

Results: (1.) Primary caregivers slightly underestimated the level of knowledge of death as a biological concept demonstrated by their healthy children in four of the six subcomponents of death: causation, cessation, irreversibility and personal mortality. (2.) Caregivers’ reasons for communicating with their children about death or avoiding the topic were loosely related to attempts to prepare or protect their children, respectively. (3. & 4.) Young people expressed ideas related to the special treatment of patients, spending time with family, judgment or discrimination, understanding, mortality, concerns about the impending death and desire to be involved in their siblings’ lives and care.

Conclusions: The quality of families’ lives concern everyone involved in caring for PPC patients. Primary caregivers and siblings often desire to be involved in communication about and interaction with patients, but not in every situation. Helping was of special interest to participants. In order to fit young people’s cognitive and active coping styles, caregivers may involve them in the care of their siblings and/or communication about prognosis. Communicating with children about death may be different than caregivers expect. When deciding whether or not to talk about their child’s impending death, caregivers may take an individualized approach influenced by their informed perceptions.
Dedication

This dissertation is dedicated to young people and families who are forced to face the end of a child’s life. It is for the resilient children and caregivers who contributed to this work as well as those who wish to learn from them.

Figure 1: Artwork created by a PPC patient (Boucher & Downing, 2011, p. 92)
Acknowledgements

The real inspiration for this project stemmed from time spent playing with and talking to the young people, staff and families at George Mark Children’s House (GMCH) in California. I thank GMCH for welcoming me as a big sister and friend.

I could not have begun this journey without my supportive supervisors Glynn Owens and Rod MacLeod. Their encouraging enthusiasm, compassionate ears and advice enabled me to turn my dream of expanding knowledge in paediatric palliative care (PPC) into reaching out to families with this document and others.

I am continually filled with awe of and admiration for the participating families I got to meet and develop relationships with. I am eternally grateful for the tears and little epiphanies I had the privilege of witnessing and experiencing before and during the interviews.

This project was a holistic, interdisciplinary endeavour. The advice of new friends from the Paediatric Palliative Care Team at Starship Children’s Hospital (especially Karyn Bycroft, Ross Drake, Jess Jamieson, Janet Nicolson, and Lorna Wood) as well as the Nursing, Education, Counselling, Population Health, Clinical, Developmental, and Health Psychology departments at the University of Auckland and various medical and support organisations were invaluable to the development of this research. I am grateful for the resources provided by the University of Auckland, Winifred Gimblett Award, Friends of the University of Auckland US/NZ, and Elizabeth Ewing scholarships.

I was also surprised by the generous offering of time and wise advice from Andrew Thompson, Claire Cartwright, Joanna Stewart, Fiona Pienaar, Heather McDowell, and Eva Morunga. Their wisdom ensured the safety of participants and preserved the accuracy of the research. Others that have helped beyond their call of duty include Gail Gillies at the Children’s Research Office, Cynthia Ward at True Colours, Wayne Ferguson at Child Cancer Foundation, Shona Harvey and the Family Support Team at Heart Children, Lorna Dyall, Jane Skeen, Mata Forbes, Mary Ann Powell, Judy McFall, Liz Hardley, Robin Dixon, Myra Bluebond-Langner, and the principals and teachers at Balmoral, Bayswater, Campbells Bay, Elm Park, Fruitvale, Glenfield Primary, Hillsborough, Mangere Bridge, Stanhope Road, Willowbank, Avondale Primary, Te Papapa, and Ruapotaka Schools.

I could also not have made it through this journey without the unconditional love and support of my family and friends: my father, mother and whanau who praised my epiphanies and empathised with my frustrations from across the Pacific, my flatmates who grounded me on Aotearoa, and new and old friends including Ruth Lin, Casey Mace, Luis Perez, Karen Siah, and many others from near and far. I am so thankful for those who have compassionately listened to me growl and watched me tear up papers. Thank you for saving me from insanity as I attempted to synthesise and verbalise the incredible lessons my participants taught me.
**Epigraphs**

*It’s hard to smile with false intentions,*  
*My face laughing blankly,*  
*Instead inside I feel*  
*The tears are building*  
*Soon I will drown them all*  
*In the flood*  
*Lift my head, wave goodbye*

Written by adolescent PPC patient (Wollington, 1988, p. 12)

*I want to talk about angels. I have two things to tell you about angels. First, there are lots of them out there and they are on the loose at Christmas. The other thing about angels is that they don’t have headlights.*

Written by five-year-old sibling of SIDS victim who died on Christmas out of his sight (Trözzi, 1999, p. 114)

*“You have not known grief until you have stood at the grave of your child”*  
(Abraham Lincoln as cited in Armstrong-Dailey, 1993)

*Dear God,*  
*What is it like when you die? Nobody will tell me. I just want to know—I don’t want to do it.*  
*Your friend,*  
*Mike*

(Ida Marie Martinson, 1976, p. 97)
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Abbreviations

CUHLI  Children’s Understanding of the Human Lifecycle Interview
EOLC  End of Life Care
GMCH  George Mark Children’s House
HCP  Health Care Provider
PICU  Paediatric Intensive Care Unit
PPC  Paediatric Palliative Care—“the active and total care of the child’s body, mind and spirit, and also involves giving support to the family” (World Health Organisation, 2008).
PPCT  Paediatric Palliative Care Team (at Starship Children’s Hospital)
QoL  Quality of life—“includes, but is not limited to the social, physical and emotional functioning of the child and adolescent, and when indicated, his or her family...sensitive to the changes that occur throughout development” (Eiser, Mohay, & Morse, 2000, p. 405).
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Co-Authorship Form

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Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work.

Chapter 4. STUDY ONE—CAREGIVERS’ PERCEPTIONS OF CHILDREN’S UNDERSTANDING OF DEATH

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<td>Rod MacLeod</td>
<td>PhD Supervisor: Supported process and edited written work</td>
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Certification by Co-Authors

The undersigned hereby certify that:

- the above statement correctly reflects the nature and extent of the PhD candidate’s contribution to this work, and the nature of the contribution of each of the co-authors; and
- in cases where the PhD candidate was the lead author of the work that the candidate wrote the text.

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Chapter 1. INTRODUCTION

1.1. Thesis Overview

This dissertation begins with a brief description of the historical and ideological underpinnings of children and families in the Paediatric Palliative Care (PPC) context. It explains my own personal biases and assumptions before, during and after carrying out this project. An overview is provided in the introduction (Chapter 1).

Chapter 2 summarises the past literature surrounding children and death and addressing healthy and unhealthy children’s, adult palliative patients’ and finally PPC patients’ perceptions of death. Chapter 3 justifies the methods.

In Chapters 4, 5, 6, and 7, studies associated with the aims of this paper are justified, described and discussed. Chapter 4 addresses Study One, a quantitative study which compares healthy children’s perceptions of death to the perceptions their primary caregivers believe they hold. Chapter 5 explains Study Two, an interview study of the opinions of families and whanau involved in PPC. Chapter 6 refers to Study Three, ethnographic research with PPC patients and siblings. Chapter 7 addresses Study Four, interviews of the siblings of PPC patients.

In conclusion (Chapter 8), a brief summary of the research and outcomes is provided followed by possible implications and directions for future research.
1.2. Context

People generally feel sympathy for doctors who have to deliver terminal prognoses. This sympathy may not be apparent, however, in those who receive the unwelcome news (Bearison, 2006). When the terminal patient is a child or adolescent, the situation becomes increasingly complex. Increasing life expectancies (Stillion & Papadatou, 2002), more accurately described as decreasing infant mortality (Ferrarini & Norström, 2010), perpetuate the myth that older people always die before children (Reynolds, 2006). As a result, the event of losing a son or daughter is ranked among the most stressful of all bereavements by twentieth century researchers in New Zealand (Shouksmith, 1985) and internationally (Himelstein, Hilden, Boldt, & Weissman, 2004). Adding to the difficulty of the situation, the death of a child challenges beliefs in a just world (Stillion & Papadatou, 2002). It may affect the child, the child’s family, friends, caregivers, and even strangers in a profound manner (Himelstein et al., 2004). Increasing caregivers’ knowledge about communicating with children at and about the end of life is worthy of investigation.

During PPC patients’ lifetimes, numerous needs must be met. Not only are patients dealing with physical needs, but psychosocial needs may increase when they receive news about their impending death. Deciding how to communicate within and to families in these situations is not a black-and-white matter. Each member of a family will be likely to have a different view of the situation, necessitating the role of mixed methods research. Due to the fortunate infrequency of PPC patients (Himelstein et al., 2004), however, there are not many specialists in this area, so it may be difficult for caregivers to know whom to turn to for advice.
Perceptions of Life and Death in Paediatric Palliative Care

The treatment of children in end-of-life situations is important to society. It affects not only children, but their nuclear and extended families, whanau (Metge, 2001), friends, peers and others who know them. Though millions of children are forced to cope with life-threatening illnesses each year (Himelstein et al., 2004), they are still seen as a medical rarity. About half of childhood deaths result from chronic extended illnesses (Stillion & Papadatou, 2002). In New Zealand, 1-2 of every 10,000 children require PPC each year (Jones, Trenholme, Horsburgh, & Riding, 2002). The infrequency of conditions which require PPC explains why data for assessing the prevalence of individual life-limiting conditions in New Zealand are limited. Despite this, the way doctors, nurses and care staff in clinical and home settings provide PPC to children with chronic illnesses makes a huge difference to the lives of those in the community and especially to those they work to help. Conditions which affect children include malignant and non-malignant illnesses. Unlike adult palliative care, most PPC illnesses fall into the second category (Hynson, Drake, Knapp, Madden, & Fowler-Kerry, 2012), making it a unique form of care. Therefore, it has been suggested that researchers look beyond studies of cancer and specific heart conditions. Unlike more predictable adult palliative care conditions, those of PPC patients include congenital anomalies, physical and mental impairments, and rare pulmonary, neurological, and metabolic diseases (Hurwitz, Lewandowski, & Hilden, 2008).

Paediatric palliative care “is the active and total care of the child’s body, mind and spirit, and also involves giving support to the family” (World Health Organisation, 2008). PPC is for children for whom curative treatment is no longer appropriate and may extend over years (Jones et al., 2002), unlike adult palliative care. Research in the field of children’s palliative care is paving the way to more comfortable and less painful lives for children (Gaab, 2008). PPC providers in New Zealand and elsewhere would like to incorporate research into their
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work (Starship PPCT, 2009). They believe that families could benefit from more evidence-based practice.

PPC includes end of life (EoL) treatments which are focused more on alleviating patients’ suffering. However, unlike palliative care for adults, PPC symptom management may be administered alongside curative, life-prolonging treatments (Amidi-Nouri, 2008). Caregivers appreciate this hope-sustaining approach of simultaneously providing both curative and comfort-promoting treatments to patients, allowing parents to buy time while minimising pain (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007). As mentioned, despite the obvious benefits, improving survival rates of children with conditions such as prematurity and cancer may offer false hope to caregivers that children’s deaths can always be prevented (Himelstein et al., 2004). Childhood infirmities are common and often treatable. Less than two decades ago, the founder of Children’s Hospice International Armstrong-Dailey, noted that “Only one percent of children with life-threatening illnesses are getting hospice care” (Stephenson, 2000).

Families of children who seek PPC suffer from a variety of diseases and carry high symptom burdens (Drake, Frost, & Collins, 2003). More specifically than earlier stated, an estimated 1.41 children per 10,000 children in New Zealand require palliative care services each year (Jones et al., 2002). Based on past prevalence rates, it has been predicted that 276 children and young people will benefit from palliative care in the year 2016 (Naylor, 2011), with the number growing to 284 in 2026.

Caregivers of PPC patients must balance their hope for a cure with that of relieving symptoms and accepting an inevitable death, carrying on with the expectation that their child will live forever may not be the most realistic, sustainable coping strategy. Though cancer is not the only disease managed by PPC, it is one of the major illnesses and demonstrates trends
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common to most other PPC-qualifying illnesses. Paediatric oncology patients make up less than one third of referrals to PPC in contrast with adult PC referrals, of which cancers compose a larger group. Over the last several decades, childhood cancer patients have experienced a significant improvement in survival (Youlden et al., 2011), making patients less likely to qualify for or seek PPC. In recent years, one out of every 640 adults was a survivor of childhood cancer (Hewitt, Weiner, & Simone, 2003). This may perpetuate the fighting spirit of many families who never want to give up the hope of lengthening their child’s life (Himelstein et al., 2004). Less than one-fifth of parents from a sample of US and UK families with a child with terminal cancer (with less than a 30 percent chance of cure) chose to end cancer-directed therapy (Bluebond-Langner et al., 2007). Almost half of the children in the study who died received some cancer-directed therapy within the last month of life. Though this may not be the case with other illnesses, most caregivers of oncology patients may never give up their hope of curing their children’s illnesses.

The inclusive family-centred approach of PPC currently accommodates both caregivers who accept their children’s impending deaths and those who do not. It is obvious that caregivers’ reactions will likely facilitate their children’s future treatment and may be influenced by family members, friends and health care providers (HCPs). The factors which drive caregivers’ acceptance or refusal to accept may affect the way PPC is delivered to their families, perpetuating a cycle of caregiver-HCP-treatment interactions.

Studies of children at the end of their lives are also usually disease-specific. While precise, the application of these studies may be problematic, considering that PPC teams work with children with a wide variety of illnesses, including rare life-limiting conditions. It would be next to impossible to address every family in the context of their child’s illness
considering the obscure nature of some PPC patients’ diseases (and thus, the reason for limited cures available to treat them).

Despite increasing rates of cancer survivorship, cancer is still the most prevalent single cause of death from disease among children aged one to nineteen (Smith et al., 2010). Its incidence increases annually, though it makes up less than two-fifths of PPC patients in New Zealand (Jones, 2002). The high prevalence of cancer may be due to delayed exposure to infectious agents which cause leukaemia or due to enhanced detection and reporting of low-grade brain cancers resulting from the wider availability of magnetic resonance imaging of the CNS in the 1980s.

Though cancer affects the largest group of children referred to PPC, the majority of referred children have neurodegenerative, metabolic, genetic or congenital conditions (Vadeboncoeur, Splinter, Rattray, Johnston, & Coulombe, 2007). Many PPC patients suffer from complex chronic conditions; illnesses anticipated to persist for at least one year. Chronic diseases may be progressive, relapsing-episodic, or constant (Seiber, 2005). Complex chronic conditions (CCC) include cardiovascular, congenital/ genetic, gastrointestinal, hematologic/ immunological, malignancy, metabolic, neuromuscular, renal, and respiratory diseases (Amidi-Nouri, 2008). Children who qualify to receive PPC may be those who are seeking curative treatment that may fail (cancer, heart disease, etc.), children who require intensive long-term treatment to maintain quality of life (QoL) including those with HIV, cystic fibrosis, and muscular dystrophy; children with progressive conditions including metabolic disorders, trisomy 13 or 18, osteogenesis imperfecta; and children with severe disabilities which make them vulnerable to health complications (severe cerebral palsy or prematurity, anoxia, brain malformations, etc.) (Himelstein et al., 2004). Because of the cognitive effects
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diseases may have on PPC patients and their families’ reactions to them, mixed methods or creative research methods may be required to access the voices of young people.

The prevalence of various diseases depends on several factors. Ethnicity, socioeconomic status and culture have been shown to be associated with various health outcomes (Adler, Boyce, Chesney, Folkman, & Syme, 1993). New Zealand is a unique, multicultural society composed of many ethnic groups including (ordered by proportion) New Zealand European, Māori, Chinese, Samoan, Indian, Cook Islands Maori, Tongan, English, and Korean (Statistics New Zealand, 2007). As a result, the unique, multicultural society of New Zealand provides for an equally diverse trend in illness prevalence. New Zealanders of Maori decent show especially high rates of illness, as reflected in the PPC population (Table 1). These factors may be taken into account when approaching families about communication with their children about death. To maximize the comfort of participants, Maori research companions may be consulted for advice and families may be approached at locations they prefer.

<table>
<thead>
<tr>
<th>Ethnicity (%)</th>
<th>Disease</th>
<th>Cancer (%)</th>
<th>Cardiac (%)</th>
<th>Congenital (%)</th>
<th>Other (%)</th>
<th>Total (%)</th>
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<tbody>
<tr>
<td>Maori</td>
<td>91 (26)</td>
<td>32 (35)</td>
<td>10 (11)</td>
<td>24 (26)</td>
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<td>207 (59)</td>
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<td>Pacific Islander</td>
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<td>37 (11)</td>
<td>82 (24)</td>
<td>99 (28)</td>
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Table 1: Number of children (0–17 yrs) likely to have required palliative care during the period 1996–1998 by disease group and ethnicity. Graph modified from Jones (2002).
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Children’s diseases and the ethnicities of their families are not the only factors to consider when addressing the question of how to speak with PPC patients about their health. PPC patients’ differing personalities, values (spiritual, religious and cultural), cognitive abilities, well-being, histories, ages, levels of education, socioeconomic statuses, peer interactions, resources, and surrounding current events (Liben, Papadatou, & Wolfe, 2008) influence the way they are treated by Health Care Providers (HCPs), friends, and family in the context of their conditions. While HCPs may recognise a child’s impending death an average of about six months before the child’s death, parents were found to generally begin to understand that their children will die about three months before (Hendrickson & McCorkle, 2008). This may prevent families from accessing PPC services or limiting their time to mentally prepare for their children’s deaths. If prognoses were made known earlier in the course of the illnesses, it is possible that extra time could facilitate the acceptance of a child’s death. Though a few studies have been conducted of adults’ desires to receive prognostic information (Clayton, Hancock, Butow, Tattersall, & Currow, 2007), young people’s thoughts about communication are less known. Studies of adults’ reactions to prognosis will be mentioned later because of the lack of child-focused research.

Kübler-Ross (1983) stated that children who die young are our greatest teachers. Though widely criticised (Crandell, 1985) and only touching the tip of the iceberg in terms of paediatric death research, her groundwork is indispensable to studies of death and dying. As one of the first physicians to research end of life care and a rather spiritually-focused writer, she believed that humans “are allowed to die when we have taught what we came to teach and when we have learned what we came to learn” (Kubler-Ross, 1983, p. 37). This is not reflected in the research though, as most of the current studies of dying children are based on the perspectives of nurses, doctors, and parents. Very few dying children or their siblings are
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approached by researchers to be interviewed. This is a consequence, in part, of the number of barriers that prevent researchers from accessing children’s voices. To date, much of the research does not directly address children’s concerns. Very few studies assess young people’s perceptions of the concept of death, their or their caregivers’ emotional states during the dying process, or the nature of their diseases. It is from this well-intentioned land of the unknown that our studies of communication within the context of PPC arise.

1.3. Assumptions/ Personal Bias

When I was 15 years old, my mother read a newspaper article about the grand opening of a home for very sick children on a hill in San Leandro, California, the city next to my hometown. At that time, I had provided childcare, taught swim lessons and religious education, tutored, peer counselled or mentored most of the children in my neighbourhood. My only experiences with children in medical settings were in visits to people I loved: my own friends and family. The thought of entering a place where children went to die deeply saddened me. However, I was intrigued when my mother invited me to visit the house with her.

The opening celebration of George Mark Children’s House, the first independent children’s end of life and respite care facility in the United States, was beautiful. On that sunny day in 2004, clowns blew bubbles toward children in wheelchairs as the staff welcomed us and showed us around the art room, music room, playroom, and children’s bedrooms of GMCH.

I began as GMCH’s first “peer volunteer” that year when I turned 16 (the required age to volunteer). I was nervous and excited to be a part of a new way to provide care to families
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facing one of the most difficult things in the world: the death of a child. My naivety blinded me from understanding that providing care to PPC patients is about much more than the tragedy of death. However, as I spent week after week at the house, my eyes were opened. I learned from the children, nurses and families not only about the huge challenge they face in caring for a very sick child, but of the quality of life that good care enables them to have.

PPC at GMCH takes a family-centred approach. Adults make decisions for their children about the course of their treatment and what the younger members of their families are told or not told. On a few occasions at the house, I was asked to play with siblings in the garden, art room, or one of the family suites while their brother or sister was actively dying. Their parents had chosen not to include or inform their other children (including siblings) of the dying process that was going on. I respected their choice and carried on playing with siblings, avoiding answering the siblings’ questions about why they could not see their parents or the patient sibling directly. Another volunteer once told me that the siblings “don’t really know what’s going on. Kids are so resilient.” I wondered if parents avoided discussing death with their sick children as well. During my five years volunteering at the house, a few patients asked me about heaven, yet also talked about having children of their own when they were “grown-ups.” I wondered what sort of awareness they had about their impending deaths and how/ if they talked about it in their families. These conversations fuelled my interest in developmental and health psychology.

Being raised and educated primarily in the United States, I come from an individualistic culture that values independence and autonomy. Having begun my studies of child psychology as a very tall child (I began babysitting before age 12, teaching religious education at 14 and teaching swim lessons at 15), I came to believe that children hold their own, strong opinions and views of the world. Their voices are both influenced by those of
their families and whanau, and exist independently of them. After providing childcare at early childhood centres in New Zealand and the United Kingdom and working with children as a play therapist (in New Zealand) and sister, teacher and friend (in several countries), I affirm those beliefs.

My Catholic upbringing and experiences as a sibling may also affect the way I view death and communication in family systems. To me, the family is a highly influential social institution and a rich source of developmental knowledge. Having a family history of cancer and a mother, older brother and younger sister who have undergone numerous medical surgeries for other illnesses has made me aware of the strain families are put under when dealing with medical issues. Being the well sister of medically-involved children and the daughter of medically-involved caregivers over various stages of my childhood and early adult life further strengthened my sense of self-sufficiency and encouraged me to take on helping/ caretaking roles outside of my family.

In New Zealand, there are several organisations supporting children and families who have been through or are experiencing issues around illness in the family. I have been involved with two of them. The Seasons programme supports young people and adults dealing with grief, loss and change. The programme consists of small groups of young people (of ages five to 18) who meet after school for nine weeks. The activities the young people do together aim to help them understand and cope with loss in a safe way, working with peers who are experiencing similar things. As a Seasons facilitator, I have had the privilege of listening to children, adolescents and parents talk about the ways in which they have dealt with the loss of siblings and other family members over the duration of my PhD. In contrast, Radio Lollipop is a programme which aims at distracting children at Starship Children’s Hospital from their medical concerns with fun games, songs and art projects. The volunteers
visit children in their wards or down in a radio station room in the hospital atrium. Volunteer work for these two organisations over the last three and a half years has coloured my experience as a PPC researcher and helped me understand the “real world,” everyday experiences of children in New Zealand.

This research is influenced by my expectations that children are capable of holding views independent of those of their care providers despite their dependencies on them. Having worked at GMCH and with families in other contexts in and outside of New Zealand, I also recognise that children and their families’ lives are highly interconnected and utilise the strengths of family-centred approaches in my mixed-methods research. As most current PPC practice is based on the recommendations of experiences HCPs, scientific inquiry of the care recipients through a health psychology lens may offer a different perspective. After identifying the concerns that families are willing to express to a sensitive researcher outside of the system of care, more rigorous methodology will enable clinicians, families and communities to more fully understand and promote the voices of children involved in PPC.
Chapter 2. LITERATURE REVIEW OF CHILDREN’S CONCEPTS OF DEATH AND ADULTS’ UNDERSTANDING

2.1. Literature Review Overview

In order to gain information about children’s understandings of death, primary caregivers’ interpretations of it and communication within families receiving PPC, in addition to the University of Auckland’s multi-database search engine, the current literature was reviewed though the following databases: Child Development and Adolescent Studies, GoogleScholar, Index New Zealand (INNZ), JSTOR, MedLine (OvidSP), PsycInfo, ProQuest Psychology Journals, PsycArticles, Psychology and Behavioral Sciences Collection, PubMed, ScienceDirect, Scopus and the University of Auckland theses and dissertations collection.

Combinations of the following main key terms and variations of them were searched, primarily through the databases at the University of Auckland: “P(a)ediatric palliative care,” “children’s hospice,” “prognosis,” “terminal illness,” “end of life,” “children,” “young people,” “adolescents,” “siblings,” “parents,” “primary caregivers,” “family,” “communication.” Less frequent searches of the following terms and like words were also conducted: “childhood cancer,” “muscular dystrophy,” “chronic illness,” “information sharing,” “sensitive communication,” and “P(a)ediatric intensive care unit.”

2.2. Healthy Children’s Views of Death

In the past, physicians and health care providers generally agreed that children under the age of ten years were not capable of conceptualizing death (Spinetta, 1974). They believed that children did not worry about the fatal nature of illnesses because they did not have the capacity to do so. It was argued that young children did not fear death, though they
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feared falling from high places and loud noises (Kubler-Ross, 1983). However, some noted that children displayed an “inner knowledge of death” through symbolic language (p. 126). A fully “mature” understanding of death was believed to come only after the children reached their adolescence (Silverman, 2000, p. 48).

2.2.1. Age/Stage Perceptions of Death

Several theories have been proposed to explain how children gain an understanding of death over time. These age/ stage theories do not always agree on the periods of developmental progression towards death understanding. It is still generally accepted that most children between birth and six years of age do not have the mental capacity to conceptualize death. Children at this age are very concerned with separation (Morrissey, 1963; Stillion & Papadatou, 2002), however, and children’s fears are often studied alongside their developmental understanding of death. Slightly older children (aged six to ten) are primarily afraid of physical injury and mutilation, though they do not usually experience death anxiety as a fear of the end of life until after age nine or ten (Morrissey, 1963). Many researchers believe that children as young as three years old see death as a changed state, children from five to six see it as a universal event, and those between eight and nine understand that they will die someday (Kenyon, 2001). Death understanding, however, may not develop in parallel with fear of death (Slaughter & Griffiths, 2007), and it is possible that this tendency of researchers to link children’s understanding of death and fear may reflect a bias stemming from adults’ cultural interpretation of death.

Piaget set out developmental milestones on which others proposed the earliest theories of death understanding. From his theory of cognitive development, one may infer that toddlers between the ages of one and two, while still in the “Sensorimotor” stage, view death as a separation (Piaget, 1962, as cited in Stillion & Papadatou, 2002). Although Piaget
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proposed a more stage-like, sequential theory of development than an age-based one, he suggested approximate ages at which developmental milestones might occur. According to his framework, children between about three and six-years-old, in the “Preoperational” stage, view death through an egocentric lens of magical thinking. They may believe that the dead can come back alive. It is not until they reach the “Concrete-operations” stage (between age six and twelve) that they achieve a mature concept of death. Researchers following Piaget propose that once in the “Formal operational” stage (about twelve years and older), children may become concerned with spiritual issues at the end of life, much like adults do (Stillion & Papadatou, 2002).

Based on Piaget’s early observations, Kane (1975) suggested that children organise information they know about death based on their cognitive stages between the ages of three and twelve. She proposed that children in the first preoperational stage recognise death as a structure or position (horizontal body). They next understand death as a state of non-functionality during their concrete operational stage (as proposed by Piaget). In the formal operational stage, they finally see death as an organised process. Though not always explicitly stated, it is clear that death understanding does not occur at specific ages, though general ages correlate with concept acquisition. This is especially important in our application of death understanding to PPC populations, where a child’s developmental stage may not be predicted by their age. Whether the acquisition of death understanding is stage-like, in congruence with Piaget’s theories, or a gradual process resulting from experience and physical development is uncertain. It has been established, however, that death understanding relates to cognitive development.

One’s appreciation of approaching death is also believed to develop with age and cognitive ability (Bauer, 1976; Shu & Shih-Fen, 2006). Nagy (1948) observed age-related
changes in her studies of children’s understandings of death. Her research suggests that children of five years and younger are generally concerned with death as separation, six to nine-year-old children see death as avoidable, and children aged 10 and older see it as final but still avoidable. One may note, however, that Nagy’s research was conducted during a critical point in history when death was more commonplace than others; wartime. Kane’s (1975) above-mentioned sequential model of death understanding development suggests that children realise that death exists at age three. Children aged three to six may see death through a “here and now” lens; as an event that causes separation and immobility. She observed that seven to nine-year-old children see death as a more concrete, irrevocable, universal event that is caused by certain factors and leads to rendering a person’s body dysfunctional. The oldest group she observed, children aged ten to twelve, were assessed as understanding death as an abstract and logical happening. These stages each came as young people’s cognitions developed.

Findings from these early studies have been questioned. Many conclusions from early studies were drawn from personal observations rather than objectively measured data (Spinetta, 1974). For example, it has been noted that Piaget based several of his theories on observations of his own children. Others using scientific methodology asked leading questions (Hoffman & Strauss, 1985). While most recent writers agree that children under five worry more about being abandoned than dying, children over six may understand more than researchers thought. Using a variety of research methods may allow us to get around methodological issues and assess children’s understanding in the modern NZ context.

2.2.2. Non-sequential Perceptions of Death

Hoffman and Strauss (1985) questioned such age/ stage approaches, noting that though children develop awareness of the subcomponents of death, their understanding does
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not happen in a predictable developmental sequence. The subcomponents include the necessity, causality, irreversibility, universality and cessation of death. Causality refers to the internal or external forces that cause death, irreversibility refers to its permanence, and universality refers to death as a natural law for all living things (Stillion & Papadatou, 2002, p. 300). In Hoffman and Strauss’ (1985) research, three to seven-year-old children were shown a picture of a dead dog and asked questions measuring each of the subcomponents. They found that children understood the cessation of external events (moving, speaking) in death before they understood that death involved internal events (thinking, dreaming).

Though they did not suggest that children’s acquisition of death subcomponents occurred at specific ages, they asserted that a child’s understanding of the simple subcomponents of death precede complex ones: universality precedes irreversibility, causality and cessation, which precede inevitability. Children’s level of cognitive development affects their concept of universality, but not their concepts of cessation or irreversibility (White, Elsom, & Prawat, 1978). Later theorists such as Speece and Brent (1984) generally accept that children’s death understanding is the culmination of death’s components of universality, irreversibility and nonfunctionality which may develop at different times. These concepts of universality, irreversibility, nonfunctionality, and causality interact with each other (Silverman, 2000, p. 48) as children grow to develop greater understanding.

Despite non-linear theories, many researchers still take a more sequential approach to development. Slaughter Griffiths (2007) approached their study of children’s understanding of death as a biological event in relation to their fear of death within a Piagetian framework. Their study suggests that children in the preoperational stage understand death as temporary and reversible. When in the concrete-operational stage, children may see death as universal and irreversible but only resulting from extreme causes. It is not until the formal operational
stage that Slaughter inferred that children obtain an adult view of death. The only conclusion we can be sure of from our synthesis of the death literature is that as children mature cognitively, they reach a fuller understanding.

2.2.3. Context-Related Perceptions of Death

Other researchers suggest that influences beyond age and development may affect children’s conceptualisations of death such as socioeconomic status, religion, exposure to death stimuli and culture. Tallmer (1974) found that children from families with low incomes who lived in urban areas held less-developed understandings of death than children from middleclass suburban towns. By contrast, other researchers found very small differences between children of varying socioeconomic statuses (Atwood, 1984) or no such effect (Mahon, 1993; McIntire, Angle, & Struempler, 1972). These differences could be due to differences in the degree of diversity between the groups. Alternatively, perhaps those with suburban backgrounds were exposed to private school education, which is often religion-based and may include education around concepts such as Heaven and Hell. The value participants placed on monetary assets may have also played a part as well as the decades each cohort was studied or born in.

Religion may have a stronger relationship to children’s understanding of death as a biological event. Exposure to death and death concepts through religion may conflict with a biological understanding of death. Candy-Gibbs, Sharp and Petrun (1984) found that five to seven-year-old children raised in Southern Baptist communities were more likely to see death as a reversible event and hold the belief that death is only caused by unusual things (i.e. catastrophes) than children raised in Unitarian households in the United States. It may be the case that some religious stories used to instruct children use death as an instrument of morality. Cultural and religious affiliations have been found to correlate with children’s
understanding of the irreversibility and universality of death while age has been shown to correlate with understanding of universality and inevitability. Subcomponent understandings of death may be influenced by the religious climates children are raised in.

As mentioned, socioeconomic status and religious participation may not be independent variables (Mueller & Weldon, 1975), though no clear direction has been established between them. It may be the case that children raised in more religious homes are also of higher socioeconomic statuses and therefore, have greater access to resources and education. In New Zealand, a relatively secular society (Statistics New Zealand, 2006), views of death may differ from the rest of the world, influencing the way children learn about it. New Zealand has historically had lower rates of violent crime than other countries (Kalish, 1988), perhaps also contributing to lower exposure to death through personal experiences and the media.

A study of Israeli children (Mahon, Goldberg, & Washington, 1999) found that boys as young as six-years-old had accurate understandings of death, perhaps due to their high exposure to death stimuli. Though disturbing, one might assume that children who witness death in the news and in person learn a realistic definition of death more quickly than others. Today, however, children’s exposure to real death stimuli may be decreasing. Drastic decreases in infant mortality rates account for much of the increase in average lifespan in modern, industrialized countries (Knapp et al., 2011). With technological advances and the widespread influence of the media, however, children today have exposure to death on the television, computer and on the radio. They may have less exposure to personally witnessing death, however, as people more commonly die in the hospital and often their bodies are immediately hidden from children’s views (Kane, 1975). Over 65 percent of New Zealanders
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die in institutions such as hospitals and hospices (New Zealand Health Information Service as cited in Schwass, 2005), perhaps limiting children’s direct involvement in the dying process.

This may not be important, though, as a Taiwanese study found the relationship between children’s death-related experiences and concepts of death to be insignificant (Shu & Shih-Fen, 2006). The death constructs of children who had experienced a severe illness, lost friends, relatives or animals to death, or who had been to a funeral were found not to be significantly different from those who had not. Nevertheless, the study affirmed the relationship between the concepts and gender, grade, religion and family discussions. The authors stated that children “excluded from discussions concerning the death of someone close to them and who were not allowed to participate in funeral or memorial services are likely to feel isolated, and may try to fill in missing information regarding the death with their own imaginations or by media messages, leading to negative evaluations and reactions toward death” (p. 237). These relationships between experiences with death and death understanding likely exist even in very young children (Hunter & Smith, 2008). It has been suggested that today’s children may have more to grieve about than past generations did with concerns of terrorism, war, drugs, bullying, and gender issues amplifying children’s losses (Goldman, 2004). However, most children currently participating in research are not less exposed to death than those interviewed during war time. Despite many children today being exposed almost nightly to death on the news, however, many adults still avoid and repress the emotions that death provokes (Bertoia, 1993). This exposure without explanation may affect not only young people’s emotions but their developing understanding.

It is important to note that very few studies of healthy children’s understanding of death have been conducted in New Zealand and the findings may not apply to children in today’s climate of technology. Most of the previous research mentioned before and after this
chapter was conducted in the United States and United Kingdom, cultures with slightly different expectations, social systems and lifestyles than those in New Zealand.

2.2.4. Talking with Healthy Children about Death

Discussing death with children is not generally easy for caregivers considering its taboo nature in many cultures. The majority of parents of preschool children avoid discussions about death with their children until after the death of someone close to their families (Giesenberg, 2007). It may be difficult for some adults to listen actively to children to understand how they see death (Dyregrov, 2008). Children may interpret the concept of death very differently to adults. Clichés about death, such as “we put puppy to sleep” and “grandma’s watching over you” may paint inaccurate pictures of death in children’s minds. Associations between mothers’ abilities to answer questions that children are likely to ask about death and children’s understandings of death are not clear (Hunter & Smith, 2008). Nonetheless, specialists advocate telling children that death is “when the body stops working” (Goldman, 2004, p. 171) and providing honest answers to their questions (p. 172).

Many children may be unafraid of death and happy to discuss ideas with researchers and friends who are willing to listen (Slaughter, 2009). For example, one little girl shared a detailed description of her cat’s death with her classmates without inhibition (Silverman, 2000, p. 54). Some propose that children do not fear death (Giesenberg, 2007). Researchers like Giesenbert (2007) posit that children are innately spiritual and creative, sometimes believing in life after death. Belief in an afterlife may lessen pre-schoolers’ fear of death, including children who have had near-death experiences (p. 142). Likewise, children may not yet be aware of social taboos surrounding death and feel free to discuss it with their peers and friends. In approaching schools for recruitment purposes, many adults report being surprised by the candid way some children talk about death. New Zealand teacher described the case of
one of her primary school students who asked her what would happen to his dead father’s body. Since discussing death with children is not a common event, it is unlikely that most teachers would know how to react to pupils’ questions.

It is worth noting that one American study found no relationship between parental discussion of death and their children’s ages or cultural/religious backgrounds (Candy-Gibbs et al., 1984). Perhaps discussing death is an event that requires prompting. The earlier-mentioned study of Taiwanese children’s death concepts, however, was strongly influenced by parent/family discussions (Shu & Shih-Fen, 2006). In that study, families who spoke with their children about death had children who felt more positively about death. Unfortunately, research on children’s conceptions of death is distant and may not reflect the understandings provoked by factors affecting children in the twenty-first century. Most studies in the area are also based in the United States (Shu & Shih-Fen, 2006).

Cohort effects are worth noting. Children today may be exposed to real deaths less than those from more traditional societies were. However, one study of Maori children in New Zealand found that parents do not hide death from their children (Jacob, 2011). Instead, caregivers who participated in the study claimed to talk openly with their children in age-appropriate ways. They included children in the grieving and funeral processes as a way of supporting them through whanau connections. Children in NZ may have a unique trajectory of death understanding in comparison with traditional European cultures given the influence of the Maori population.

A few decades ago, parents were often encouraged to exclude children from ceremonies associated with the death of a loved one (Goldman, 2004, p. 176). Some practitioners now believe that attending memorial services helps children by empowering them through exposure. When children are able to gain knowledge about situations, one might expect them to be able to judge them more accurately. Teaching children about death
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helps them gain knowledge and learn to cope (Silverman, 2000). Children may still be primarily gathering information about death from other sources such as their peers and the media, however, and their concepts of death may be most strongly influenced by life experiences (Candy-Gibbs et al., 1984). Many children are “bombarded with loss” (exposed to death through the media and large social networks) today, yet they are still often excluded from conversations about death (Goldman, 2004, p. 168). By not including children in those conversations, adults may be suppressing their expressions of irrational fears. Unfortunately, this can lead to children attributing death to causes such as “naughtiness,” bad thoughts (Sourkes, 2007) or being unkind (White et al., 1978). Since many adults are believed to avoid discussing death with their children (Giesenber, 2007), children’s concepts may be limited and/or distorted.

Educators who understand children’s health issues and awareness of them may provide schools and medical professionals with information they may use to educate the children (Harrell, Bradley, Dennis, Frauman, & Criswell, 2000). The topic of death is not a comfortable or clearly-defined concept to explain to young people. The lack of research of children’s perceptions of death may be due to adults’ reluctance to talk about it with children, though death may affect young people in profound ways (Reynolds, 2006). The “elephant in the room” (Fearnley, 2010), the topic too uncomfortable to discuss but which those present are aware of, may be caused by caregivers’ lack of competence and/or confidence. The unintended effect may prevent them from supporting children through traumatic events. When coping with the impending or current death of a family member, caregivers may miss opportunities to support children if they do not understand their perceptions and needs.
2.3. Unhealthy Children’s Views of Death

Experiential and emotional factors may be important in assessing a child’s understanding of death. Experiences in health care settings may be of particular significance in the development of the death concept. Orbach et al. (1985) administered questionnaires to children of various ages and levels of cognition. He reported that as children age, they reach higher levels of cognition and that their levels of anxiety increase surrounding the concept of death. Whether this finding can establish causation or is simply a correlation without direction has not been established. In light of Orbach’s findings, one might infer that environments where children with terminal illnesses usually live (e.g. the hospital, the medical-equipment-filled home, etc.) are likely to foster more mature conceptions of death than the typical environments of healthy children. Most children have very little exposure to death in the home (Kane, 1975) and most healthy children’s earliest encounters with death involve the death of a grandparent or pet. Children from Orbach et al.’s (1985) study understood the concept of human death better than that of animal death. All the children rated their anxiety in relation to human death higher than anxiety in relation to animal death. Understanding death in relation to the self may be a necessary step in forming a mature meaning of death. If this understanding is brought about by increased exposure to medical facilities and tools, it is plausible that paediatric patients may understand death more maturely than others. However, Orbach et al.’s (1985) findings conflict with Slaughter and Griffiths’ (2007) more recent findings of the association between mature death understanding and lower levels of death fear, so may provide some degree of assurance that a developing knowledge of death is not detrimental.

Many unhealthy children and their siblings make frequent hospital visits which may allow them to build relationships with other paediatric patients and give them greater access
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to information about death (Bluebond-Langner, 1978). Ward and clinic friendships may develop between families and children (Skeen & Webster, 2004) and the ramifications of one child’s disease progression may affect others. Children may listen to conversations of adults speaking about them in order to get information about their disease, despite parents’ attempts to hide the information from them. Place (2000) noted that adults may socially regulate children’s bodies when they are critically ill. They may do this by covering up medical equipment they depend on or ignoring hospital interruptions. Adults may want to protect children from knowledge which they believe will cause children pain. Children in the hospital are especially susceptible to this practice, as intravenous drips and other technological aids are likely to be involved in their treatment. In contrast, children generate their own meanings about their bodies in the medical context. A child may consider a machine a part of their body, saying things like “I’m beeping” when communicating with nurses about their needs. Unhealthy children who are “medicalized” this way may view mortality differently from healthy children.

2.3.1. Quality of Life

How experiences in healthcare settings, understandings of death and quality of life (QoL) relate remains unknown. QoL is a relatively new term and QoL in children has not yet been uniformly defined. Bradlyn (1996) defines QoL as including, but not limited to “the social, physical, emotional functioning of the child and adolescent, and when indicated, his or her family, and it must be sensitive to changes that occur throughout development.” The QoL of children under eight-years-old is usually reported by their parents or medical practitioners. If appropriately defined, children may able to self-report QoL. An appropriate tool is still needed to enable them to express their state (Eiser et al., 2000), enabling HCPs to address concerns. Language and phrasing is fundamental to the development of this tool.
Healthcare providers and researchers are starting to recognise the value of obtaining self-report information about children’s health, functioning and emotions (Cremeens, Eiser, & Blades, 2006). Several tools are being developed to do this, though their creation is still in its infancy. Measures include the ExQoL, a 20 min test for six to 11-year-olds comprised of 12 pictures delivered to children over a computer with vignettes read aloud (Eiser et al., 2000). Children are asked how much they are like the child in the story and how much they want to be like the child in the story. The ExQoL has been found to demonstrate acceptable internal reliability and validity and distinguishes between children with asthma and healthy children. Other measures include the PedsQL (weighted towards issues concerning children with cancer and asking children to assess about the severity of problem areas using smiley faces) and the C-QoL (containing separate child and carers’ forms) (Jirojanakul, 2003). It may be important to measure QoL in children in order to support children’s needs, assess changes resulting from interventions and address issues related to psychosocial context of children with serious medical conditions. QoL tools could be used to compare outcomes associated with telling children about their impending deaths and withholding information from them. They may also be useful in assessing the effects of disability on disclosing prognosis and developing interventions in future research.

Despite having perhaps a more mature understanding of the medical world (and possibly the concept of death), young children who are ill may not have impaired QoL. In a self-report study of Thai children, QoL was not correlated with disease state (Jirojanakul, 2003). QoL scores of children were not affected by their health between chronically ill, acutely ill or severely mentally ill groups. However, research in the field of children’s QoL is very new and few validated measures exist. Illness and level of death understanding may not extend into other areas of children’s lives. If this is the case, there is a lot of hope for children
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facing difficult medical issues. If adults understood that QoL is not affected by one’s understanding of the death concept, they may be less afraid of discussing death with ill children.

Children are capable of learning, remembering, reporting, and applying information. The work of Seigal (1990) demonstrated that children could understand concepts of contamination and contagion when questions were related to situations which children could visualise. Children as young as three are able to learn about the cause and management of asthma and can actively contribute to management of their condition (Holzheimer & Mohay, 1998). By adolescence, over half of a sample of eight to 19-year olds demonstrated patterns of self-management of their type I diabetes (Schilling, Knafl, & Grey, 2006). Children may be able to self-report their QoL (Eiser et al., 2000). Experts recommend encouraging children to express their emotions and views to help them deal with change and loss (Rollins, 2005, p. 218). How telling children about their illnesses or impending deaths affects their QoL remains uncertain.

2.3.2. Understanding of Death Concepts

A child’s understanding of personal mortality may relate to their levels of cognition and experiences in the hospital and with death. An ethnographic study of patients in an American paediatric oncology clinic concluded that children formed their self-concepts based on the information that they were given or gathered for themselves (Bluebond-Langner, 1978). Children began by seeing themselves as unhealthy children. They then became hopeful children in remission from a temporary disease. After they relapsed, they began to understand the permanency of the illness. Most of them eventually progressed to viewing the illness as a cycle which would eventually end in death. Paediatric oncology patients may have formed most of this theory from their exposure to the medical world. The children’s
knowledge of their impending death, whilst perhaps not affecting their QoL (which was not measured), certainly affected their interactions with caregivers. They tended to guard the well-known “secret” from conversations as fiercely as their parents did to avoid distressing them. Though the theoretical constructs suggested by Bluebond-Langner (1978) were considered, they were not used as the basis of this research as her ethnographic research participants consisted of younger oncology patients several decades ago in the United States.

While studies of unhealthy children’s death communication with their caregivers about death concepts are not common, it has been established that some sort of relationship between cognitive development, life experiences and death understanding exists. There may be a clear association between five to ten-year-old children’s concepts of personal mortality and their levels of cognitive development as well as between their concepts of personal mortality and their death-related experiences (Reilly, Hasazi, & Bond, 1983). It has been argued that without an explanation of death, sick schoolchildren may resort to fantasising about what death might bring, which could be more frightening than the truth (Macmillan West Midlands Paediatric Team, 2005, Table 4.1). Regardless of the age and most other demographics, conditions and experiences are likely to influence unhealthy young people’s understandings of death.

2.4. Issues with Adult Others’ Interpretation of Children’s Views

Communicating with children is influenced by adults’ preconceived notions of childhood. Young people may be perceived as qualitatively different from older family members and research participants.
2.4.1. Young People as Research Participants

In order to research young people, some researchers argue that children must be seen as equal beings in their own right rather than tokenistic humans who are on their way to becoming adults (Carter, 2011). Children are located physically, socially, culturally and discursively within shifting grounds of power, positioning and contexts. The complex position in which children are placed makes them difficult for researchers to access.

Several researchers who take child-centred approaches suggest that children should be empowered through research (Christensen, 2004b; McPherson & Thorne, 2000; Powell & Smith, 2009) while remaining protected and respected (NZ Ministry of Health, 2006a). Young people’s stigmatised reputation is due in part to the socially-constructed term “childhood,” which polarizes children and adults, classifying them as competent and incompetent social actors (Thomson, 2007, p. 183). The term has evolved greatly over time (Valentine, 2004), however, and children are no longer viewed as little adults. Many people now view children as dependent, innocent, and separate from adults. Ensuring that their opinions are heard is still a complex process. One aim of children’s research is to challenge the silencing of their voices in the social sciences, often with the intention of discerning their needs to improve the quality of care that they receive.

Unfortunately, overprotecting children may develop from a perceived ethical responsibility to defend them (Powell & Smith, 2009, p. 133). Though most young people may want a say in things that affect them (p. 139), much of the research conducted in order to promote understanding of child issues has excluded children and relied on others to gain their perspectives. This may be problematic since there may be poor correlation between child and adult reports (Reynolds, 2006). Children’s direct participation in matters concerning them is important when their experiences differ from adults who may try to speak on their behalf.
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(Adams, Theodore, Goldenberg, McLaren, & McKeever, 2010). Despite survival rates being poor measures of medical success for PPC patients, children’s accounts of their experiences are rarely sought (Eiser & Morse, 2001). Children may be able to report their experience better than the academic and medical worlds believe. Experts recommend encouraging children to express their perceptions (Rollins, 2005).

Issues of consent, access, privacy and gatekeepers have severely restricted the research methods applied to study hospitalised children (Coyne, Hayes, & Gallagher, 2009). Ethics documentation varies with regard to researching children in New Zealand (Powell & Smith, 2006). Different university and other ethics committees require different levels of consent and precautionary actions to ensure that children are protected from invasive, harmful research. Practical and organisational aspects may also hold back the process of collecting data from children (Coyne et al., 2009). However, some researchers advocate giving children the same or similar rights as adult participants. They point out that viewing children as passive victims only excludes them from research, further inhibiting them as active social beings. The vast majority of research with children in hospitals comes from Scandinavia, the US, and the UK. As a result, studies of New Zealand children are limited, especially medically-compromised children.

2.4.2. Young People and Patients as Informants

Children receiving paediatric palliative care (PPC) may feel even more marginalised than children suffering from other conditions and treated like passive objects (Dunlop, 2008). In places like the Paediatric Intensive Care Unit (PICU), the child’s body is often connected to machines and seen as containing separate social/human and technical/non-human elements (Place, 2000). The child’s medical equipment may be monitored more than he or she is, causing him or her to feel lost or invisible. One patient commented, “He [the doctor] just
talked to mum and I’m thinking ‘Hello, I’m sitting here’; it was like I was sat dead on the bed. He was talking to my mum and he could have been talking to me” (Young, Dixon-Woods, Windridge, & Heney, 2003). Doctors who talked directly with children gained their trust (Kelsey, 2007). There is very little research which illuminates children’s voices in death research, though adults’ interpretations of their children’s thoughts do not always compensate (Eiser & Morse, 2001; Reynolds, 2006).

There are very few children’s voices expressed in recent death research and, as mentioned, adults’ interpretations may not fully compensate (Reynolds, 2006). Though it is assumed that children, caregivers and HCPs trust each other, there may be trust issues between or within any of those groups. The doctor-caregiver and caregiver-child relationship may not parallel each other (Bearison, 2006), so it is difficult to know what each party understands about the frequently changing situation as the child’s illness progresses. Some researchers acknowledge a need for educating parents about their children’s cognitive abilities to understand the consequences of a death experience on their child (Ellis & Stump, 2000). Adults do not know what children know about death but express strong interest in learning how children think and feel about death (Kane, 1975).

In a study of the effect of parenting a child on adults’ beliefs about the development of children’s death concept, Ellis and Stump (2000) found that parents believed that the concept is developed at an earlier age than did nonparents at a university in Tennessee. Psychology undergraduate parents and nonparents were asked “At what age do you think children (your child included) realize that death is a permanent state (that is, that death is not reversible)?” The parents sampled also tended to believe that children’s concepts of death develop at an earlier age than most researchers revealed. The research was limited by Ellis and Stump’s (2000) method which did not compare within-group differences between parents and their
own children’s death understanding. Despite the limitations, the findings of Ellis and Stump’s study may be drawn upon to make implications for non-parent healthcare providers. HCPs who are not parents may not realise the extent of their children’s knowledge about death whilst those with children may think they understand death from an earlier age. More research is needed in this area before clinicians may apply them to their practices.

Caregivers with children in the hospital receiving PPC may not only be unsure of their children’s understanding of impending death, but their communication and behaviour may be swayed by what they believe medical personnel want to hear. Families of PPC patients in a recent study in the United States tried very hard to be well-liked by the staff who cared for their children (Amidi-Nouri, 2008). They believed that isolating the staff could cause isolation of their child and diminish the quality of the child’s care. Thus, doctors and nurses may both directly (through speaking with their patients) and indirectly affect the amount of information about illness and death that children receive. HCPs may play a central role in teaching PPC patients about impending death both independently of and through children’s primary caregivers.

Generally, researchers of PPC collect data by questioning medical personnel, nurses and occasionally doctors, even with studies of children’s spirituality (Davies, Brenner, Orloff & Sumner, 2002; McPherson & Thorne, 2000). This is problematic because HCPs may confound their own opinions with those of the children. They may also have only cared for the child over a brief period of his or her end of life (EOL) process. As a result of the hidden curriculum underlying medical training (preserving life / physical health at all costs), patients and family members may be depersonalized (Browning, Meyer, Truog, & Solomon, 2007). Nurses and doctors may also avoid making an emotional connection with families because, according to one doctor, empathising makes the situation more draining to deal with
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(Browning et al., 2007). Even families may not accurately interpret children’s views. What parents think their healthy children need may not correlate with what the children themselves report needing (Monterosso, Kristjanson, & Phillips, 2009). Some researchers attempt to overcome this issue by obtaining children’s voices though their behaviours, artwork, and words as interpreted by paediatric nurses (McPherson & Thorne, 2000). The effects of agency and power may need to be accounted for to understand the perspectives of PPC patients. These concepts are not clearly incorporated in most research to date.

The location of families receiving PPC makes listening to children’s voices and communicating with them difficult. Care received by families is frequently fragmented between hospital units and within institutions (Amidi-Nouri, 2008). Hospitals are sometimes far from ideal places for difficult conversations. Medical facilities are often hierarchical environments with isolated social workers in which emotional standards of care have not been established (Browning et al., 2007), adding to the difficulty of talking about sensitive issues. Studies of the perspective of the families and especially children involved in PPC are currently missing from the literature (Amidi-Nouri, 2008). In order to protect children, adult family members and researchers may exclude them from participating in matters that concern them.

2.5. Telling Palliative Care Patients of Death

Coming to terms with death is a great challenge for a person of any age, containing moments of distress and heightened self-awareness. Owens (1997) noted that people who are told of their approaching deaths sometimes display psychological problems. In particular, anxiety and depression are common adult reactions to facing one’s own death or the death of
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a loved one. However, some patients describe their last days as “‘the best time of their lives’” (MacLeod as cited in Schwass, 2005, p. 24). MacLeod also notes that “‘there would be value in talking about death and dying more in schools,’ as a first step in bringing death more openly into our lives.” Generally the death of a child is considered so tragic that its discussion is often avoided in paediatric literature as well as medical and academic training institutions (Kane & Primomo, 2001).

The effects of learning of, experiencing and processing the children’s deaths are rarely talked about and far from understood. It seems obvious, though, that children’s dying process may profoundly affect children and their families. Children may want more information than their caregivers want to share with them (Stillion & Papadatou, 2002). Despite many parents’ beliefs, communicating with children about their impending deaths or that of siblings may actually decrease psychological problems and isolation (Hilden, Watterson, & Chrastek, 2000). In one study, 19% of families with terminally ill children acknowledged the child’s impending death to them (Goldman & Christie, 1993; Skeen & Webster, 2004). Most families blocked the discussion, believing that the child was not aware of what was going on, or did not know how their children felt or what they knew. Many parents mistakenly believed that children could not understand the magnitude of their illnesses or that they were better off spared the burden of such knowledge (Skeen & Webster, 2004). Isolation, distrust, distress and poor psychosocial adjustment have been some outcomes associated with keeping children’s diagnoses from them (Skeen & Webster, 2004).

One component that may block parents or caregivers from seeking PPC or talking about death with their children is prognostic uncertainty (Liben et al., 2008). It is not always clear which diseases have no realistic possibility of being cured. For this reason, parents may think that discussing death with their children is not appropriate, as it may crush their
commonly mentioned “fighting spirit” (Cordova et al., 2003). This is not the only option, however. Caregivers can maintain hope for a miracle cure and pain relief alongside accepting the reality of a child’s impending death.

As noted, no one knows exactly how children understand death. It is commonly held that death is not an innate concept; children develop an understanding of death as a biological event over time. Most researchers agree that by adolescence, children have an adult conceptualisation of death. This places adolescent palliative care patients in awkward social situations regarding decision-making. Patients’ primary guardians may have the power to make medical decisions for them, yet some children’s reasoning skills may be as mature as those of adults. The communication of adolescents’ diagnoses and prognoses may be kept from them if their parents wish to hide the information from them. However, talking with adolescents about death and dying may be advantageous them and their families/whanau (Lyon et al., 2010). Avoiding communication may leave End-of-life (EoL) goals unfulfilled due to providers’ fears of provoking negative moods by bringing up the topic (p. 28).

Specialists advise that honesty, trust and respect are essential in maintaining effective relationships between HCPs, patients and families (George & Hutton, 2003). Almost all HCPs experience difficulty with regard to truth telling when death is inevitable. These tensions may be based on three beliefs: (1) Honesty will bring death closer by removing hope, (2) Talking about death only leads to unnecessary distress, (3) Talking about death only gets in the way of living. George and colleagues (2003) argue that allowing young people to express emotions facilitates the exploration and correction of misconceptions that dying adolescents might hold. It also allows them to focus on their remaining time and allows their families to be more involved in helping them live comfortably.
Terminally ill (adult) focus group participants commonly expressed that “If one has more time to prepare for death then they have more control over whether their own death is good or bad” (Steinhauser et al., 2001). It is unknown as to whether this is true for children. Families in a study in California indicated that doctors were overly hesitant to bring up the possibility or timing of their child’s death (Amidi-Nouri, 2008), yet the families felt hopeless resentment toward doctors who were blunt about the child’s death. It seems that there is not a good time to bring up the topic. It is unfortunate that patients and family members are rarely consulted or included in research on communicating bad news (Browning et al., 2007), either. Additionally problematic, there may be a lack of research to aid families once they are faced with difficult EoL decisions. Statistics on topics such as EoL decision-making often go unreported (Mitchell & Owens, 2004).

2.5.1. Examples of Practice with Children

In New Zealand and the United States, primary caregivers are usually the first to be informed of a child’s impending death (PPCT, personal communication, November, 2009). The Paediatric Palliative Care team at Starship Children’s Hospital in Auckland approaches families regarding talking to their children about their prognoses from the time they begin working with them. They offer advice to help caregivers explain children’s prognoses to them by opening conversations with questions. For example, the social worker mentioned that she asks primary caregivers questions such as, “What do you think your child understands or knows about what is happening?,” “Have you spoken to your child or have you thought about speaking to your child?,” and “What does your child understand about the new team coming into his/her life?” She reports being open to conversation and makes it a standard practice to initiate the discussion of PPC but judges (from experience) if the topic is simply too painful. When that is the case, she sometimes senses parental distress and explores the reasons for the
distress. She tells those who do not want to talk with their children about death what the limited research says and what the team believes and asks parents what they would like her to tell their children if the child asks them a direct question about the prognosis. She softens the conversation by telling parents that it takes a lot of courage to open up sensitive conversations and that they know their children best so will make the best decision out of love. “Clinical intuition” plays a big part in guiding conversations between the PPCT and caregivers as well as those between the PPCT and children.

When guiding parents and other caregivers with patients and their siblings, the PPCT offers a variety of suggestions. They suggest utilising a range of books around the topics of change, death and grief such as “Lifetimes” (Mellonie, 1991). They recommend that parents include them as a part of their daily routines around quiet times. The books allow parents to gently bringing up the subject and then being “guided by” the questions or comments that may come up as part of the discussion about the book. They also encourage families to seek counselling and therapeutic play and to talk with members of the Consult Liaison Team (which coordinates specialised child and adolescent care for young people and their families).

The PPCT counsels primary caregivers as well, talking to them about using “giving words” to open conversations with their children (Starship PPCT, 2012). They sometimes give suggestions and allow parents to practice saying what they will say to their children to a member of the PPCT. PPCT Nurse Karyn Bycroft often begins conversations by telling caregivers things such as, “Other families have found these words useful in talking with their children…” PPCT Social Worker Jess Jamieson exemplifies this by suggesting to parents of older children and teens to say things like, “You just got rushed down here by ambulance and helicopter. When you arrived you were very sick and too ill to talk to me. I was very scared and I wondered what you would want us to do if they weren’t able to get you through this. I
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think we need to talk about that. What would you want us to do if ever we couldn’t hear your voice?” The greatest tool according to Jamieson is just having a compassionate listener who is not afraid to open the conversation about death and to allow parents to explore their options. Thus far, clinical experience has been a necessity of the PPCT to be able to say what has worked for others in similar situations and how they felt about it. The standard practice of the PPCT regarding communicating children’s prognoses is mainly based on clinical experience and studies of families outside of NZ. This current research aims to give HCPs and parents an even greater range of experiences to draw from.

2.5.2. Examples of Practice with Adults

Communicating prognoses to children opens up conversations about their pre- and post-death wishes. Though scientific exploration of these conversations is limited in the paediatric population, ideas may be generated from research of adults in similar situations. End-of-life wishes may be facilitated by advance care planning, tools such as life tubes (small capsules containing emergency instructions) (Age Concern New Zealand, 2012) or websites aimed at breaking taboos (National Council for Palliative Care, 2011). Advance care planning is an increasingly common action taken by adult patients with compromised health (National Health Board, 2011). Programmes such as “Five Wishes” allow patients to clarify who should make health care decisions when they cannot make them, the kind of medical treatment they want or do not want, how comfortable they want to be, how they want people to treat them and what they want their loved ones to know (Aging with Dignity, 2010). Advance directives are still infrequently used, however, and may conflict with what doctors or others consider the patient’s best interest at the different times (Lo, 2004). Surrogates cannot often direct others to carry out patients’ preferences. Most parents in one study of children’s advanced care planning found the process helpful because they felt it preserved
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their child’s QoL and helped them avoid unnecessary suffering (Hammes, Klevan, Kempf, & Williams, 2005). Opening conversations about young people’s prognoses may allow for opportunities to enable children to die “good deaths” (Monerosso et al., 2009).

As mentioned, opening up discussions of death is not an easy task. Less than half a century ago, (adult) patients were typically not informed of terminal prognoses by doctors (Owens, 1997). It was believed that withholding this information was “protecting” patients from distress associated with facing their impending deaths. This approach to non-disclosure is still held by medical systems in countries such as Armenia and Japan (Children's Hospice International, 2008). In Uganda, children eligible for PPC are generally not told anything about their illnesses at all. The end of a patient’s life may be perceived to signify a medical failure to general practitioners. In developing countries such as India, it may be more common to provide life support to very ill paediatric patients for longer than in other countries. The withdrawal of life support accounts for 72% of neonatal deaths in developed countries (Guglani & Lodha, 2008), making discussions about the end-of-life more likely before the time of death. Studies conducted in recent decades in the US and NZ have shown a growing increase in doctor and nurses’ openness to talking about death with adult patients (Jones, 2006; Nolbris & Hellström, 2005), yet communicating with patients about their impending deaths is still not generally a standard component of care.

One survey of healthy adults inquired about their perceptions of what dying patients should be told about their prognoses (Feiffel, 1963). When asked what they believed patients should be told, the overwhelming majority stated that patients should not be told that they were dying. However, when asked if they themselves would like to be told if they were dying, the majority responded that they would like to be told. Researchers may need to contact those they aim to help directly when addressing their personal psychosocial concerns.
Today, many New Zealand doctors try to be upfront and honest to adults about patients’ prognoses. It is a challenging topic for some, as they worry that discussing death removes hope (Steinhauser et al., 2001). It is generally accepted by health care providers that patients benefit from knowing if they have a terminal illness. Patients may be empowered by being able to plan ahead when they know of their impending death, taking on tasks such as informing family members and appreciating life (Owens & Naylor, 1989). The effects of sharing information with young people remains unknown.

2.5.3. Talking about Prognoses with Young People

Though PPC is helping families improve the quality of their children’s lives, parents may still need more honest, open communication to ensure a “good death” (Monterosso et al., 2009). Most of the universal medical community agrees that sharing decision-making at the end of life is desirable (Meyer, 2008) as is the pursuit of consensus about EoL decisions without verbally asking consent. Now, with the progression of palliative services, patients take comfort in knowing that more doctors are comfortable talking about death (Steinhauser et al., 2001). Caregivers almost always believe that preparing for death is essential. However, nurses remind caregivers that “Just because a patient is dying it doesn’t mean that he has stopped living” (Meyer, 2008, p. 1705), so a balance between EoL and “normal” activities may be desirable.

McNamara (2004) argues that the concept of a “good death” may be considered outdated. She states that the original “good death” of the original hospice movement necessitated open communication and acceptance of death. This concept, however, has been abandoned in favour of a philosophy of a “good enough” death, a death facilitated by the physical management of symptoms. This switch in approach from psychosocial to physical
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treatment may take doctors’ focus away from the communication needs of palliative care patients.

For many New Zealanders, the knowledge of a limited lifespan is appropriate and necessary for cultural preparation. The concept of a good death has many different interpretations (Schwass, 2005) which require awareness by individuals so they may prepare for it in advance. For some, especially those in cultures which emphasise the importance of extended family, it may mean the presence of loved ones. In some cultures, however, it is viewed as better not to tell sick people of the true nature of their condition so that it does not extinguish their will to live (p. 20). Health care providers must be sensitive and attentive to the needs of families when children are near the time of death (Truog, Christ, Browning, & Meyer, 2006). Clear communication is essential for the support of families at that critical time.

Though prospective studies of terminally ill young people’s desire to be told their prognoses before they die are unethical and sometimes impossible, their wishes are worth consideration. Nonetheless, HCPs and primary caregivers must first recognise children’s health statuses before it is possible to pass that information on to patients. A study of paediatric oncology patients’ prognostication found substantial delays between parental recognition and doctor acknowledgment that the child could no longer be cured (Wolfe, 2004). Telling patients and/or their families as early as possible is generally perceived as the most desired communication approach.

Science has moved us forward in our views of this topic. Research literature from forty years ago suggested to parents to hide the knowledge of their life-limiting illnesses from their children (Trozzi, 1999). Though it is still the case that most HCPs would not advocate full disclosure of prognostic information to children, considerations are made beyond those
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preventing children’s immediate distress. Paediatric Professor Maria Trozzi advises parents not to divulge dire outcomes to children unless they specifically ask. Ryan, a seven-year-old brain tumour victim was directly told by his parents that if the surgery he was about to undergo failed, he would probably die. His first reaction was to reassure his parents by saying “I’ll be fine” (Trozzi, 1999, p. 134). Whether this was a case of denial, innocent hope, a need to reassure his parents or something else, his reaction was certainly similar to one that would be considered socially acceptable and even “brave” if it was made by an adult. Young people may be able to cope with information about death in typically “adult” ways.

Today, practitioners generally believe that many children, including young children (Stillion & Papadatou, 2002), know when they are dying and may or may not want to talk about it (Dunlop, 2008). Regardless, some specialists suggest that caregivers should be willing and able to discuss their children’s impending death frankly (Himelstein et al., 2004). The British Medical Association endorses responding to children’s clear questions with honest answers and offering information to children who seem willing to know it (GMC, 2001 as cited in Dunlop, 2008). Excluding children from conversations about the seriousness of their illness may affect how much they trust their caregivers (Stillion & Papadatou, 2002). One of PPC children’s immediate needs is knowing that at least one of their parents will always be there with them (Silverman, 2000).

Dunlop (2008) recommends that professionals react with sensitivity to the child’s behaviour and family dynamics. Children who do not ask questions about death may still be aware of their impending deaths. Caregivers of PPC patients may feel that they have failed at their jobs as the protectors of their children and want to avoid harming them further. Some believe that this includes “protecting the child[ren] from the truth” (p. 30). However, when
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children are ill, knowing the seriousness of their illness may help them cope with changes, cooperate with doctors and adhere to treatment regimens (Silverman, 2000).

A recent study of bereaved parents (Kreicbergs, 2004) obtained information from 429 of the 561 eligible parents in Sweden whose children had died of cancer between 1992 and 1997. They asked the parents “whether or not they had talked about death with their child” and whether or not they regretted having that conversation. Of the 147 parents who talked about death with their child, none of them regretted it. However, of the 258 parents who did not talk with their children about death, 69 parents (27 percent) regretted not having that conversation. 47 percent of parents who believed their children were aware of their impending deaths regretted not talking about the impending death with their children. Parents who did not sense the awareness of death in their child were less likely to regret not talking to them about it. Though the culture of Sweden is not the same as that of NZ, parents’ avoidance of death conversations based on their children’s levels of understanding may reflect international behavioural trends.

Most empirical research in the area of discussing prognosis with PC patients, however, is outdated and not child-focused. Now that medicine enables children to live even longer with illness, more studies of reactions to prognostic information are needed (Himelstein et al., 2004).

2.6. New Zealanders’ Views of Death

Many factors influence the way people approach death including the culture, beliefs and age of the dying person. Most cultures view the death of a child as an untimely tragedy and have an extremely difficult time accepting the death of a child (Schwass, 2005). Doctors’
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Religious traditions and cultures influence their understanding and personal response to suffering and death (Kane & Primomo, 2001). New Zealand is a multicultural nation consisting primarily of Pakeha (European New Zealander), Maori, Pacific Islander and Asian residents. In the most recent New Zealand census, an estimated 52.5 percent of children aged 0-18 years old were European, 18.7 percent were Maori, 9.3 percent were Pacific peoples, 7.9 percent were Asian, 0.9 percent were Middle eastern, Latin American and African (MELAA), 7.4 percent composed the “Other” category and 3.3 percent made up the “Unknown” ethnic group (Statistics New Zealand, 2006). It is through a multicultural lens that NZ families must be viewed.

2.6.1. New Zealand Maori Concerns

McCreanor and Nairn (2002) point out a paradox observed when interviewing non-Maori doctors about Maori patients: “all patients must be treated equally, that is, they must all be treated as individuals, yet all individuals are different!” (p. 5). Failure to address cultural-specific health issues in any culture may result from overvaluing individuality. Such is the case in Maori health research.

Involving Maori in health research is critical (Health Research Council of New Zealand, 2008) to ensure that the tangata whenua, native people of New Zealand, are accurately represented. Researchers cannot assess whether clients’ needs are being met without collecting data about them. Of the 2,122 deaths of New Zealand children aged 0–17 years who were eligible for PPC between 1996 and 1998 (Jones, Trenholme, Horsburgh, & Riding, 2002), 26 percent were Maori. Maori children are sadly disproportionately represented in PPC statistics.

Just under 15 percent of the population of New Zealand (Rochford, 2004) and 9 to ten percent of Auckland (NZ Ministry of Health, 2006b) is of Maori decent, yet Maori are
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overrepresented in many negative social and health statistics. A higher percentage of Maori have not completed school, are unemployed, have a personal income of less than $10,000, receive government benefit, live in households without telephone or motor vehicle access, live in homes they do not own, experience household crowding, smoke, binge drink, smoke marijuana regularly, and are considered overweight or obese (NZ Ministry of Health, 2006b, pp. 21-28). The infant mortality rate is more than twice as high for Maori as it is for non-Maori, with many of the deaths attributed to Sudden Infant Death Syndrome (p. 55). The gap between Pakeha and Maori chronic illness outcomes, their presentation in the health sector later in the course of their diseases, and their significantly more severe conditions (Rochford, 2004) make recognising the needs of Maori in PPC research especially important.

The relationship between life and death is unique within a Maori world view (Edwards, McManus, & McCreanor, 2005). Long-established traditions around death are normal and part of daily existence (Edwards, McCreanor, Ormsby, Tuwhangai, & Tipene-Leach, 2009). The principals of tapu and mana (words often mistakenly simplified and defined as “sacred” or “spiritual”) warrant particular understanding and sensitivity from those who care for PPC patients and families. Some advocate that health researchers should take care to avoid viewing Maori participants through the “colonial gaze,” (Edwards et al., 2005, p. 3) which may provoke anger and fear from Maori families, in turn causing them to discontinue their involvement in research and further disadvantage them. There are several practices in which many Maori engage and traditions they follow at the end of a person’s life (Tikanga Chief Advisor, 2003). A Maori view of death may differ from those of other cultures.

Similarly, there may be ways of coping with serious illness that are Maori-specific. As Maori people rely on their whanau for love and support (Metge, 2001), illness or death
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affecting one member weakens the family network as a whole (Schwass, 2005). Since the most vulnerable family members are the focus of special support, the loss of a child, or “whare ngaro” (Mikaere, 2002) (Mikaere, 2002 as cited in Edwards et al., 2005, p. 5) may be especially painful. The death of a child in combination with deep-seated colonial issues, financial strain, common drug issues and a fairly stoic male culture may put enormous strains on Maori fathers (Edwards et al., 2009). Bereaved Maori parents may feel guilty and need outside support (McCreanor, Tipene Leach, & Abel, 2004), according to an analysis of themes arising from caregivers who looked after Maori families who lost a child to sudden infant death syndrome (SIDS). PPC providers must be sensitive to their protocol for the tangi (funeral). Supporters should be aware that bereaved parents may believe in “mate Maori,” the Pacific and Maori notion of the past coming back to haunt people through their children (McCreanor et al., 2004). Health beliefs may affect the way Maori people approach discussions and behaviours when forced to face an impending death.

Maori children’s views of death may differ from non-Maori, as they may take a part in all aspects of nurturing the sick and saying goodbye to the dead (Schwass, 2005). Sharon Clair of the New Zealand Nurses Organisation noted the lack of the fear of death by Maori children resulting from exposure to the dead. When sitting with the body of her uncle, she describes how “‘the kids would come in when no-one else was there. They’d pull back the cover and look at his fingers, and touch his hands or face... There was no fear –it was a natural part of the way we live and are’” (p. 41). Internationally, it has been found that allowing children to be present at the death and subsequent ceremonies may enhance their coping skills (Lauer, Mulhern, Bohne, & Camitta, 1985). In Maori families, children are generally welcomed into the marae (sacred meeting house), the most appropriate place for protecting the dignity of the tangi (Rangihau, 2009). Many children in Maori families are
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included in death practices and supported by whanau networks that help them cope with grief resulting from their losses (Jacob, 2011). Jacob’s (2011) qualitative study found that Maori children may be allowed to express unrestrained emotions and be informed about death and tangi. Their parents used religious and cultural ideologies to explore death concepts with their children. Death did not seem to be seen as taboo or hidden from children.
Some health concepts are Maori-specific. It is a common practice for some Maori theories of health to be taught to medical students in NZ, such as Mason Durie’s Whare tapa wha (Rochford, 2004), a Maori-specific health model. Maori, as a changing people, have reported finding themselves swept into the mainstream culture, which may be detrimental (Cooper, 1997). Given some conventional physicians’ perceived contempt towards traditional Maori healing, there is an aversion on behalf of healers to processes associated with western healing professions (Ahuriri-Driscoll et al., 2009). This concept of “Maori health” includes physical, spiritual, and mental health (Cram, Smith, & Johnstone, 2003). There are few Maori clinicians currently practicing, so it may be beneficial for non-Maori doctors to assume extra responsibilities when working with Maori clients (Cooper, 1997). Currently, many Maori clients are reluctant to interact with clinicians and feel suspicious about the treatment they receive (Cram et al., 2003). Pakeha clinicians may act in insensitive or patronising ways toward Maori clients (or clients from other cultural backgrounds). Examination of Maori practices in dealing with a child’s limited lifetime has yet to be conducted.

The principles and recommended practices in PPC run strikingly parallel to those advocated by Maori health practitioners. Like the Maori approach to healthcare, Te Whare Tapa Wha (Durie & Pere, 2009), the spiritual dimension of PPC (Davies et al., 2002) aims to
integrate mind (hinengaro), body (tianana), spirit (wairua) (Cram et al., 2003), and relationships (whanau) (Rochford, 2004). The PPC team at Starship Children’s Hospital has described their team’s role as supporting parents to “hold” their child through their illness (Starship PPCT, 2009).

Congruent with that goal, the philosophy of PPC ideals incorporates a sense of hope, self-worth, purpose and interconnectedness (Davies et al., 2002). PPC aims to improve quality of life in ways which are sensitive to children’s upbringing, culture, and community (Himelstein et al., 2004). PPC may recognise that child’s death affects not only the child’s immediate family, but their entire whanau (Metge, 2001). Unlike most medicine, it may also incorporate psychosocial and spiritual concerns. PPC may not require a lot of modification to be successfully delivered to Maori families considering the consistency between Maori and PPC health goals.

2.6.2. Pacifica Concerns

As mentioned, one of the largest ethnic groups in NZ consists of Pacific peoples. A model called the Fonofale model (Pulotu-Endemann, 2009) was developed to incorporate Samoans’, Cook Islanders’, Tongans’, Niueans’, Tokelauns’ and Fijians’ values and beliefs into the provision of healthcare to them. The model is based on workshop participants’ comments relating to illness, behaviour and mental health from the 1970’s to 1995. In particular, these groups all stated that the most important things for them included family, culture and spirituality. Incorporating the aspects of “culture,” “time” and “context” may be of the utmost importance to PPC patients from Pacific Island backgrounds. The dimension entitled “Other” relates to various other variables that may affect health such as gender, age and socio-economic status. These will be taken into consideration when interpreting families’ responses to the prompts of this research.
2.6.3. Multicultural Concerns

New Zealanders come from varied cultural backgrounds which may influence their preference of communication style. While many families want complete and honest information, some may want to receive it from the medical staff and others may prefer it delivered by a person close to them (Truog et al., 2006). Children are not included in discussions about the consequences of their diseases and impending deaths in all cultures (Liben et al., 2008). Most parents of children in China, Japan, and Greece take a more protective approach in addressing diseases, limiting explicitly open communication and involvement of young people with their illnesses. Blunt honesty about dying is seen as brutal and insensitive. Body language and eye contact are more common ways of expressing emotions, through which children may express concerns in culturally appropriate ways.

As a result of this desire to protect children, many older family members in parts of Asia and Greece are reluctant to inform children about the severity of their illnesses (Stillion
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& Papadatou, 2002). Asian and Greek parents may believe that the knowledge will be too painful for their children to cope with. The care of the dying may be a private family matter. Some people, such as those examined in a Greek study, may notice that their children are aware that they are dying and choose to indirectly say goodbye without breaking the silence (Stillion & Papadatou, 2002). People from different cultures cope with death and communication around it differently.

In some Asian cultures, it is common for parents to tend to avoid discussing death with young children (Shu & Shih-Fen, 2006). Most Taiwanese parents see death as a taboo topic and believe that children are too young to understand death and should be protected from it. It is a Taiwanese custom to view death negatively and avoid discussing it. This may stem from Taoist or Buddhist ceremonies which almost never conceal outward demonstrations of sadness or pain. In contrast, however, many early childhood teachers in Korea express the need for educating children about death (Kim, 2001). They also express concerns for whether children are at an appropriate cognitive level to hold those conversations. Though some researchers state that children should be educated about death (Lee, Lee, & Moon, 2009), there is little evidence that death education helps children understand death or enables them to deal with it. The large number of Asian immigrants in New Zealand may feel similarly diverse in their approaches to talking with children about death.

Like culture, family systems affect the way people deal with death. Single-parent families may be especially troubled at the time of a child’s death (Kubler-Ross, 1983, p. 41) without another adult caregiver in the household. Kubler-Ross (1983) suggested that single mothers may be shunned and avoided. Her research is outdated and most was not conducted in NZ, where most children are born to unmarried parents (Morton et al., 2010).
also be many other things that matter more than the way primary caregivers speak about death with their children. One study found the lack of a significant correlation between maternal response competence (parents who communicated openly about death) and children’s understandings of death (Hunter & Smith, 2008). The amount that children’s understanding of death is influenced by their communication with primary caregivers remains understudied. The belief that older people will die before younger ones due to longer life expectancies may increase the level of shock experienced by families who lose a child (Reynolds, 2006) and as the age of parents in NZ rises (Morton et al., 2010), one might expect that their levels of anxiety rise as well. The shrinking family size and its increase in fluidity make the dying and grieving processes even more isolating (Reynolds, 2006).

2.7. The Children’s Hospice Movement

The development of the hospice movement in London in 1967 (Schwass, 2005) created a need for the acknowledgement of patients’ approaching deaths. This movement fostered a desire for an understanding of the psychology of death and dying. Researchers began examining the social, health, and psychological aspects of the dying process. Elisabeth Kübler-Ross (1973) is considered by many to be a pioneer in death studies. She identified a stage-approach to grief. She noted end-of-life patients’ post-prognosis experiences of denial and isolation, anger, bargaining, depression and finally acceptance of their impending death. Kübler-Ross examines the stages of grief in families facing the death of a child in *On Children and Death* though she does not address the psychological Studies of dying children in her book. The hospice movement is encouraging people progress in their understandings of death.
The children’s hospice movement is still in its early stages of progression. The first children’s hospice, Helen House, opened in 1982 in Oxford, England (Worswick, 1993). Since then, over 40 children’s hospices have been built to cater to the needs of PPC patients in the United Kingdom and smaller numbers of children’s hospices exist in Australia, Germany, the United States, Canada and elsewhere. It has been suggested by HCPs that one of the most difficult Studies of hospice staff is getting clients to accept their services (George Mark Children’s House, personal communication, July 19, 2008; Bear Cottage, personal communication, February 10, 2012). This may be due to potential clients’ association of “hospice” with “dying” and a passive resistance to admit that a patient’s illness is terminal. Several families that initially rejected and then accepted treatment offered at GMCH, a children’s hospice in the United States, wished that they had accepted the treatment there earlier (Amidi-Nouri, 2008).

There is currently no children’s hospice facility in New Zealand, though hospice at home and palliative care services are available (Horsburgh, 2000). However, the Waikato Region in New Zealand is in the unique position of having two grief support agencies for families of children with terminal illnesses: True Colours and Rainbow Place. The agencies both showed support for the research and offered to help with recruitment. Unfortunately, grief support is not as accessible in other parts of the country (Stevenson, 2010) but the PPCT at Starship Children’s Hospital in Auckland provides PPC advice to people in the Auckland area and to the rest of New Zealand (Starship Children’s Health & Starship Foundation, 2009).

A study of the needs of children receiving PPC implied that the needs of patients depend largely on the needs of their families (Fitzgerald, 2005). The needs identified in order of importance included: “opportunities to be cared for by loving family,” “fun,” “love,” and
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being able to “talk about their feelings and fears.” It has been suggested that there may be nearly twice as many emotional difficulties among chronically ill children as among healthy children (Perrin, Lewkowicz, & Young, 2000). Some believe that these difficulties may result from caretakers’ focus on physical treatment, overlooking love and self-esteem needs (Fitzgerald, 2005). It has also been said that palliative care processes should involve on-going transitions between supportive care on initial diagnosis and aggressive curative treatment (Kane & Primomo, 2001). The transitions may also need to follow on to the time when more focus is placed on the palliative intent, hospice care and bereavement.

The holistic approach of hospice aims to address the physical, psychological, educational, social, and spiritual needs of PPC patients (Stillion & Papadatou, 2002). Achieving a sense of control may be one of the more difficult Studies desired by families. Studies of children who died in a hospital setting point out the value of allowing the child and family to play a role in the decision-making (McCallum, Byrne, & Bruera, 2000). A study conducted in Europe found that children were more likely to die at home (the location generally preferred by families) if they were older than ten years, cancer patients, or in the Netherlands, a culture which some believe is more accepting of death (Pousset, Bilsen, Cohen et al., 2009). Cohort effects, however, were not considered.

The number of years paediatricians have been practicing medicine may also affect the likelihood that patients are referred to PPC. More experienced doctors in two states of the USA were associated with decreased odds of referring children to palliative care (Knapp, Thompson, Madden, & Shenkman, 2009). There were also differing rates of referral between doctors of different ethnicities, with Hispanic paediatricians less likely to refer patients prior to the end of life. Culture and experience not only affect one’s understanding of death, but their willingness to prescribe or seek treatment.
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What parents want from Paediatric Intensive Care Unit (PICU) staff may reflect what PPC patients and families want. Parents of children in PICU who participated in one American study wanted honest information about their child’s illness, access to staff, clear and sensitive communication, emotional support, chances to continue in their support role as a parent, and support from a person of faith (Meyer, Ritholz, Burns, & Truog, 2006). One parent of a child in PICU referred to hospital staff as “the only link between you and the unknown” (p. 652). For children, however, due to most hospital policies, parents may be the only direct link to medical information. Parents may feel a little more in control with free access to information and personnel. The same link between access and control may be extrapolated to young patients and siblings in relation to their caregivers.

The holistic approach of the hospice movement aims to allow greater flexibility with regard to the spiritual, social and cultural needs of New Zealanders (Schwass, 2005). However, some see the development of PPC as disintegrated and inflexible (MacLeod, 2002) perhaps due to its infancy as a field and service. It has been claimed that the current clinical end-of-life care training offered in medical schools is inadequate not well integrated and pays little attention to home care and hospice care (Billings & Block, 1997). PPC would be greatly improved with the help of research in New Zealand (MacLeod, 2002).

2.8. Adults’ Views of Death

Adults’ views of death are influenced by their experiences. Not even all paediatricians are knowledgeable about PPC. Out of a sample of paediatricians in Florida, 29% did not know what palliative services were available in their area (Thompson, Knapp, Madden, & Shenkman, 2009). This deficient knowledge of PPC likely affects not only the doctors
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themselves, but others on the interdisciplinary team such as psychiatrists, social workers, clinical psychologists, child life specialists, therapists, chaplains, and volunteers (Knapp, Madden, Button, Brown, & Hastie, 2011). It is apparent then, that nonmedical adults are not likely to have associated (or even contemplated discussing) death with children. Numerous studies have been conducted in adult populations to assess preferences associated with the impending dying process. As mentioned in Section 2.6, Elizabeth Kubler-Ross (1973) noted that once informed of their grim prognoses, dying patients go through a series of stages before accepting their situations. Several other theorists explored concepts of anticipatory and post-mortem grief as well, describing in detail the various processes involved. John Bowlby and Colin Parkes (1970) defined the grieving process differently, but in almost similar words in four phases: shock and numbness, yearning and searching, disorganization and despair, and reorganization. J. William Worden (2009) emphasises four aspects of grief or mourning as accepting the reality of the loss, experiencing the pain, adjusting to a life without your loved one, and being able to reorganize and carry on with life. These theories have been widely questioned, however, and are no longer accepted in their entirety though they created a foundation from which researchers may explore death and dying.

Those who have more information about their health status may have a greater ability to make informed decisions. It seems obvious that they may then be equipped to achieve their health goals in comfortable and safe ways. In the case of PPC, the responsibility lies with children’s caregivers. In one study, the majority of parents of paediatric oncology patients desired as much information as possible about their children’s prognoses (Mack, Wolfe, Grier, Cleary, & Weeks, 2006). The authors propose that doctors often speak vaguely about prognoses because they worry about causing parents distress or a loss of hope. However, the parents who found the information very or extremely upsetting were the most likely group to
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want additional information. The authors did not find any effect of losing hope on the participants who had been given prognosis information. Most consumers of healthcare want to be informed of their health statuses.

Adults’ views do not necessarily reflect children’s views. As mentioned in Section 1.2, there are vast differences between PC and PPC (Papadatou, 1997). In PPC, there must be a closer level of communication and agreement between physicians and other medical professionals and families (Liben et al., 2008). Death is less common and less acceptable in paediatric communities, often making it difficult for caregivers to agree to stop aggressive treatment. PPC patients also differ vastly in terms of age and cognitive ability. For example, some young children view pain as a punishment; an indication that they did something wrong. Since pain is a complex psychological and physical response which depends highly on perception, this could make treatment especially challenging in this population. The provision of PC is different in child and adult populations.

Though it has been recently accepted that children are not just little adults, PPC patients may be in a class of their own. The new growth in the field of PPC and the only recent expansion of knowledge on associated illnesses makes it difficult to know just how these children function on a development level. While many are delayed due to their conditions, many have speculated that terminally ill children seem to have exceptionally advanced emotional capacity for their chronological age, “as if the physical and psychological stress of the disease accelerated their emotional maturation” (Nitschke et al., 1982).

Despite this, children are still highly dependent on their caregivers. The reverse may be true as well: the benefits of involving primary caregivers directly in the care of their child include decreases in grief, helplessness, guilt and anger (Bearison, 2006). Parents’ grief
following the death of a child is an enduring process. Young patients are not autonomous beings, so a family-centred approach is more prevalent in child than adult hospice.

At present, the responsibility for informing children about their prognoses rests on caregivers. Of course, the first people with access to information about children’s health are the healthcare providers. Attending physicians, fellows, residents, interns, medical students, house physicians, nurse practitioners, registered nurses, Child-life specialists, social workers and psychologists provide paediatric patients with more than steroids, tricyclics, methadone, morphine and other medications. One social worker recalls, “I spent a lot of time just sitting in the room... just providing emotional support and a lot of hand-holding and encouragement, and that was very difficult” (p. 44). HCPs may be able to best aid PPC patients through their parents considering the family-centred approach of PPC and the parents’ responsibility for holding prognostic information.

2.9. PPC Patients’ Views of Death

Making a child’s death a “good death” is complicated by a serious lack of data at the end of a child’s life (Hinds, Schum, Baker, & Wolfe, 2005). Children and adolescents are not little adults and the low incidence of severe paediatric disease makes it even more challenging to study (Halfon, 1996). Ethical concerns block researchers from accessing children at the end of their lives. The population is especially protected because of the perceived vulnerability of the young patients. End of life care may be strained due to uncertainties, emotional challenges and communication difficulties. These include uncertain prognoses, families who are unable to acknowledge the fatal nature of their child’s diseases, language barriers and time constraints (Davies et al., 2002). Other difficulties in researching
this area include the limited size of the population, the absence of a standard QoL measure for children, and the recent recognition that PPC is a field requiring examination (Liben et al., 2008). The child’s perspective has been especially ignored, perhaps due to the child’s perceived emotional vulnerability and caregivers’ great sense of not wanting to upset the young person. However, paediatric oncology patients involved in a study about their personal EOL care preferences were capable and dignified in making complex decisions (Hinds et al., 2005).

It may not be necessary to study disease-specific samples to determining PPC patients’ needs. In a literature review of adolescents’ experience of chronic illness, it was concluded that HCPs should focus on treating young people rather than their illnesses (Taylor, Gibson, & Franck, 2008), as similar themes came arose from studies of young people suffering from different conditions. Nonetheless, one question that arises frequently within families containing a child with a life-limiting disease concerns whether or not they should inform their child of the extent of their condition. Should children or adolescents be informed to help them prepare for death or will they be happier living without the burden of that knowledge (Gaab, 2008)?

Several participants in a study of the stressors of paediatric oncology patients expressed fear of death in their drawings (Rollins, 2005). Many nurses and heath care providers believe that dying children are aware that they are dying (Faulkner, 1997; Schonfeld, 1999 as cited in Stillion & Papadatou, 2002), and encourage open communication and including children in decision-making within their families (Fitzgerald, 2005). However, little empirical research has been conducted in this area. Often parents have many questions about what their ill children know and what to tell them and their siblings about terminal conditions (Faulkner, 1997).
Children facing the end of life often have exceptionally different cognitive abilities than their peers (Gaab, 2008). Children with terminal illnesses may have spent the majority of their lives in hospitals, thus restricting their human interactions to those with adults in which the children receive high levels of attention. This may foster the development of particularly high intellectual abilities (or at least high levels of specific knowledge) in children with terminal diseases (George Mark Children’s House, personal communication, July 19, 2008). On the other end of the spectrum, children at the end of their lives may also suffer from developmental disabilities, as many PPC patients have multiple disorders. For example, a child who is chronologically fifteen years of age may have the cognitive abilities typical of most “normal” children five years of age. Thus, the problem of classifying children’s levels of cognition by their chronological ages is exacerbated among those facing death. However, even when children do not fully understand the events happening around them, they may be able to sense the tension (Silverman, 2000) and may often realise when they are dying.

Adults use “personal beliefs, myths, and common sense when they deal with children who encounter death” (Kane, 1975). Due to the uncommonness and stress of the situation, caregivers of PPC patients are unlikely to be prepared. There are a number of myths adults commonly hold surrounding childhood grief and bereavement (Himelstein et al., 2004). Most do not realise that children often know when they are dying and may experience anticipatory grief (Stillion & Papadatou, 2002). Many children worry and strive to protect their parents (Hilden et al., 2000; Himelstein et al., 2004) sometimes even going to lengths to prevent them from knowing the stress they are under.

PPC patients fluctuate in their awareness of the dying experience (Sourkes, 2007). They may acknowledge their illness, understanding that they are “very sick” without referring to life or death (p. 38) or conversely they may talk explicitly about their dying. Young people
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with life-threatening illnesses may progress in acquiring a mature understanding of death long before their healthy peers (Freyer, 2004; Masera et al., 1999). In acknowledging death, they may feel tremendous isolation (Hilden et al., 2000). They may begin to grieve for those who will survive and for their loss of control (Sourkes, 2007), function, interaction, and impending death (Himelstein et al., 2004; Sourkes, 2007). Specialists advise providing acknowledgement and honest answers to ill children’s questions. Yet many people avoid raising the topic of death with children in order to protect them or because they believe children will not understand death (Bertoia, 1993). However, when not told of death, children may formulate their own theories about it.

Adolescence is a paradox for many: it is perhaps the peak of most children’s physical health, yet a time when mortality rates increase drastically (A. Harvey, personal communication, November, 2008) mostly due to engagement in risky behaviours. Adolescents may not see the importance of taking medications with painful or cosmetic side effects at a time they believe they are immortal. Seriously ill children must cope both with normal developmental challenges and the extra burden of their illness. Adolescents and young adults who are terminally ill may struggle with issues of identity and intimacy at the end of life (Stillion & Papadatou, 2002). They may ask questions such as, “Who will I be?” and “Where does my health situation lead?,” which may involve concerns about the dying process (p. 303). A convenience sample of adolescents recently diagnosed with cancer reported being most concerned about relationships with friends and family and adjusting to the diagnosis (Decker, Phillips, & Haase, 2004). Sexuality was also of concern, though not rated as highly as the above-mentioned. Adolescent PPC patients may have specific concerns when coping with impending death.
Ill adolescents may want to be involved in EOL decisions. In a study of 11 to 18-year-old cancer patients who had outlived their prognoses in Belgium (Pousset, Bilsen, De Wilde et al., 2009), nearly all participants agreed that children have a right to know when their prognosis is terminal. The adolescents surveyed took EOL issues seriously and most of them wanted their parents to be involved. This raises the question of who should assess young people’s constantly evolving ability to comprehend their situations (often accelerated by their experiences with chronic illness). Children admitted to the hospital who are expected to die are often deemed too young to be involved in decision-making; another study which surveyed Flemish physicians who signed the death certificates of one to 17-year-olds (Pousset et al., 2010) reported that medical EOL decisions were made with input from parents 85.2 percent of the time, but from paediatric patients in only 15.4 percent of cases. Only one of the 165 children studied was considered to “have the capacity for decision-making” by the doctor (Pousset et al., 2010, p. 552). A study of 20 paediatric oncology patients in the USA and Australia who were involved in decision-making at the end of life was recently conducted (Hinds, Drew, Oakes, Fouladi, Spunt, Church & Furman, 2005). When asked about HCPs, the patients praised those who explained the situation fully to participants and gave them written information. Young people often want to have information and some decision-making power with regard to medical treatment.

Children’s illness trajectories, personalities and coping skills, and whanau’s behaviour determine their responses to life-threatening illness (Trozzi, 1999). Their developmental levels, experiences with death, and communication patterns also play a role (Stillion & Papadatou, 2002). Some children may ask their families/whanau or doctors directly if they are going to die (Bluebond-Langner, 1978; Hilden et al., 2000). However, many children do not use words. They may act out emotions in indirect ways, such as play, or they may write...
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stories to express their feelings. Behaviour, play and art may indicate a child’s awareness of death (Bertoia, 1993). One terminally ill nine-year-old boy drew a picture of his family crying, explaining “I didn’t include myself, because at the time I was in the hospital, and I didn’t think I’d be back in the picture” (Sourkes, 2007, p. 39). Some studies suggest that even when children are not told about the nature of their disease, they are aware of its potential fatality (Stillion & Papadatou, 2002).

Some children may verbalise their knowledge candidly. One eight-year-old expressed: “I know I’m going to die very soon and just have to talk to somebody about it” (Kubler-Ross, 1983, p. 21). Personal mortality is usually understood by children with serious illness (Bluebond-Langner, 1978; Reilly et al., 1983; Wolfe, 2004). Though Trozzi believes that children do not carry “unfinished business,” they may withdraw from their families and friends to signal finality (1999, p. 140). These behaviours may prompt whanau to celebrate the children’s lives with them, participating in “anticipatory commemoration.” This may take the form of allowing the child to use their life savings (which they may put towards a toy) or participate in the “Make A Wish” program (Make-A-Wish® New Zealand, 2009).

It is not always the case that families involved in PPC want as much information as possible. Caregivers may have distinct informational needs when discussing prognosis and EOL issues which are different to those of the patient as was found in the case of terminally ill adults and their caregivers (Clayton, Butow, & Tattersall, 2005). One study found that parents of PICU patients want their questions answered at their own pace (Meyer et al., 2006). PPC patients may feel the same. Children and families communicate with each other and PPC providers in ways appropriate for their individual cultures and values (Stillion & Papadatou, 2002). Common practice in NZ may not allow families to direct the pace of information given to them by HCPs, so reactions to the
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varied messages are unpredictable. Developmental levels, experiences, personalities, and available sources of support affect the perceptions and coping of patients.

PPC patients’ and their families’ perceptions of death may be affected by the amount of time they have to think and communicate about it. The length of the dying process affects families’ perceptions of the quality of their child’s death (Hendrickson & McCorkle, 2008). Since parents and dying children both want as much time as possible with friends and family, increasing the time between terminal diagnosis and death may help both parties cope. This contrasts with HCPs’ preferences for brief deaths, which shorten the time of their discomfort (Hilden et al., 2001).

Regardless of their level of awareness, children may long for normalcy or withdraw from family life (Sourkes, 2007). One 11-year-old girl wisely stated “If kids are normal, not sick, they like to be treated special. But if kids have a disease, they wanted to be treated normal” (Sourkes, 2007, p. 40). Specialists in New Zealand advise the importance of “normalising” family processes and helping children manage their own health (Jerram, Raeburn, & Stewart 2005). This may not only help PPC patients but parents and siblings as well in coping with their situations. More research is needed to determine PPC patients’ views of death.

2.10. Siblings of PPC Patients’ Views of Death

Little is written about the siblings’ reactions to PPC patients. However, the emotional costs of having a very sick brother or sister may be significant (Trozzi, 1999). One person’s health condition often affects all the other members of and relationships within one’s family (Murray, Kelley-Soderholm, & Murray, 2007). When a child is very ill, siblings may suffer from a lack of attention. Their parents are likely to be preoccupied with the patient, putting siblings at risk of developing depression. When discussions of mortality are involved, the situation becomes even
more complex. Young people may interpret what they are told literally, so euphemisms about death may confuse or mislead them (Trozzi, 1999). Young children may not be able to understand their siblings’ illnesses (Houtzager, Grootenhuis, Caron, & Last, 2004). A 10-year-old sibling felt very confused about her brother’s diagnosis, stating “I don’t know what to think... I am hearing a lot of mixed messages... everyone is telling me different things” (Sourkes, 2007, p. 38). As a result of not being left in the dark, siblings may mistrust those who care for them and develop unrealistic fears, such as catching the illness themselves (Houtzager et al., 2004). An effective program for parents of chronically ill children included a session which emphasised involving siblings in caring for the sick child and not overlooking them (Jerram et al., 2005). Preparing children for a sibling’s death may ease the bereavement period (Hilden et al., 2000).

There may be more similarities than dissimilarities between children’s and adults’ patterns of grieving (Dyregrov, 2008). Siblings may experience many issues similar to those of Kübler-Ross’ (1973) stages of grieving including denial and isolation as well as bewilderment, jealousy, and fear of dying. They may also experience guilt for surviving, and / or resentment because of caregivers were channelling all attention towards the ill child (Trozzi, 1999). Children’s relationships with their dead or dying siblings are determined in part by things that influence the relationships between all siblings: the difference in age, gender, and personality between the children. The pattern of grief the living sibling expresses may also be influenced by the relationship they had before and during the terminal illness (Martinson, 1976). Though siblings’ grief has been examined in reaction to their brothers’ or sisters’ deaths, their needs during their siblings’ illness are less clear. Psychosocial problems in siblings of oncology patients may be long-lasting. Siblings show internalising and externalising problems and may benefit from increased social support (Houtzager et al., 2004). Where this support comes from, how it is delivered and who delivers it remains unknown and these factors are likely highly context-specific.
Siblings of PPC patients living at home may be taught to be more self-reliant and may gain wisdom from dealing with their unusual circumstances. One American father speaking of his young, healthy daughter reported, “Jenny’s smart. She understands what’s going on and has adapted herself... She’s six going on sixteen. She’s a big help to her mom” (Amidi-Nouri, 2008, p. 133). The compassion and caring exchanged between patient and sibling is often disregarded despite the importance of sibling relationships in a family (Sourkes, 2007). One sibling of a terminally ill child reported “...no one cares about me just because I’m not physically sick” (Kuttner, 2007). Many siblings of cancer patients in a New Zealand study mentioned that they sometimes feel scared or worried about their siblings and would like to have information about what it is like for other siblings of cancer patients and how they can help (Dobson, 2007). Siblings’ views are certainly worth taking into consideration.

Caregivers’ concentration of attention on the dying child may lead to siblings feeling jealous, rejected, and/or angry. Siblings may feel guilty for holding these negative emotions and in turn, feel inhibited from telling adults their concerns (Macmillan West Midlands Paediatric Team, 2005). One study found that 42 percent of children between seven and eleven years old who had a sibling with cancer reported impaired emotional quality of life, doubling that of the 21 percent who reported impaired QoL in the control group (Houtzager et al., 2004). The researchers found that younger siblings had more difficulty coping than older siblings of oncology patients. Considering that this is also the demographic group with whom caregivers have the most difficulty discussing death, this may be problematic. Young people’s QoL is likely to be affected by their siblings, especially when their siblings are terminally ill.

Siblings may be concerned with their positions in the family as illnesses often cause lasting consequences on family relationships. Families who made fewer transitions between locations of EoL care tended to experience less financial stress and contain lower levels of
psychological burden (Burge, Lawson, Critchley, & Maxwell, 2005), though very few studies have been conducted of children transitioning from home to hospital to hospice (Amidi-Nouri, 2008). Changing the location of the sick child may increase patients’ and siblings’ questions about the disease and possibly death and dying. Internationally, most children who meet the criteria for PPC die in the hospital (Cochrane, Liyange, & Nantambi, 2007). Compared to most Western countries, the proportion of children who die in hospitals in NZ is low (Jones et al., 2002). How this affects siblings’ coping is unknown.

More has been written about bereaved siblings than about siblings’ experiences during the time that their brothers or sisters were living. It has been reported that siblings’ grief is often overshadowed by parents’ grief, siblings may experience “survival guilt” (feeling that they should have died and not their sibling), and siblings need assurance that the death is not their fault (Coleman & Richmond, 2009). However, caregivers and parents still lack high quality, specific information about how to help siblings during their ill siblings’ lives (Monterosso et al., 2009). Research suggests that parents need help not only caring for their sick children, but the sick children’s healthy siblings as well. The siblings may need help making sense of their illness and expressing their feelings. They feel loss just as deeply as adults (Reynolds, 2006) and may need their losses acknowledged.

Follow-up support may be needed after a sibling loses a brother or sister regardless of how they prepare for that loss. Siblings who participated in a support group generally found discussing feelings helpful when coping with a brother or sister who had cancer, even when their siblings’ illness eventuated in death (Nolbris, Abrahamsson, Hellstrom, Olofsson, & Enskar, 2010). Empathising with other siblings in a therapeutic group was perceived as very important: “It was good to hear how others felt.” Participants expressed gratitude for learning that one can experience happiness even when going through a difficult time: “Even though he
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died, you don’t have to be sad your whole life; you can be happy.” Siblings of ill children may benefit from support before, during and after a child’s death.

Young people’s coping styles may not mirror those of adults. Children may maintain a dynamic, spiritual connection with the deceased (Silverman, Nickman, & Worden, 1992 as cited in L. Goldman, 2004). This may not be a negative psychiatric symptom, but a catalyst for healing (Sourkes, 2007). As opposed to a process of severing ties with the dead, grieving is sometimes now viewed as a process of redefining one’s spiritual and emotional relationship to the dead (Reynolds, 2006). Much exploration remains to be done in discovering the needs of PPC patients’ siblings.

2.11. Talking with Children Involved in PPC about death

The question of how to best talk with children about death is yet to be thoroughly explored. Medicine and the provision of health care have much to offer, having evolved rapidly over the last century, enabling HCPs to engage in evidence-based practice. Research is also informing changes in adult palliative care and the treatment of healthy and medically-involved children. It has been argued that children were under medicated for pain until recent years (Schechter, 1989). Some researchers suggest that children’s pain has not been addressed as well as the pain of adults due to a difference between incorrect assumptions about, attitudes toward and inadequate research and training around pain management (Walco, Cassidy, & Schechter, 1994). Some might suggest that it was not socially acceptable for children to attend funerals or be diagnosed with depression until the last few decades or for adults to be given their prognoses, either. These perspectives have been challenged and reversed, thanks to a growing body of empirical research and its application.
It may seem obvious that when receiving knowledge of a child’s impending death, the child’s caregivers should be the first notified of the news. It is also seems natural to believe that communicating with children is different than that with adults. However, why this is the case and what makes children’s views different from those of adults remains unclear.

As outlined, children’s understanding of the world changes over the course of their development through their experiences. Many theorists have attempted to categorize and predict children’s cognitive, moral and emotional growth (Saarni, Campos, Camras, & Witherington, 2007; Turiel, 1998). The ways children react to and perform expressive behaviour are thought to facilitate emotional development, which is believed to develop in children from a very early age, facilitating the way they gain knowledge about their social worlds. A frequently voiced argument is that their style of communicating must be framed in the context of their culture. These studies, however, do not always apply to children’s understandings of death.

It seems obvious, however, that children’s knowledge about death is accumulated as they develop cognitively, psychosocially and physically within their environments. The rate and trajectory of their development varies tremendously. This, along with the diversity of their illnesses, makes research difficult to generalise.

Based on common beliefs about the dependency of children on adults (they are certainly not autonomous beings from the beginning), it might be argued that caregivers should be enabled to filter information to them. If this is the case, then researchers are only one step away from accessing those who communicate with children about death. Learning of how others interact with their children about such topics and how young people want to know about them may help caregivers to make informed decisions about how they might best approach children when addressing prognostic information.
A practical approach to accessing the experiences of families in New Zealand is thus needed. In attempt to help caregivers figure out if they are communicating too much or too little with their children, we conduct four research studies.
Chapter 3. METHODS

3.1. Methodology Overview

It has been suggested that using a combination of methodological approaches is becoming increasingly popular because no single method captures the richness of children’s (or any individuals’ experiences (Coyne et al., 2009). Many methods of gathering and analysing data have been used or interpreted wrongly (Lowe & Ryan-Wenger, 1992; Thomas, 2011). Healthcare consumers have been led to make decisions based on misleading studies or those which set out to “prove” a theory, such as the link between MMR vaccinations and autism (Wakefield, 1999). Using a range of different methods may help validate the data (Heary & Hennessy, 2002). Complex, multi-faceted issues such as those faced by families receiving PPC may be best examined with mixed-methods research.

It has been proposed that research addressing communication with children about the possibility of their death “is dated and ...new research from the perspective of the children would advance knowledge for practice” (Dunlop, 2008). Though there is much to be learned from foundational death studies, it is plausible that today’s climate of technology and wide-reaching media may change children’s perceptions because of the quicker transmission of information with minimal censorship. Even “innocent” media such as children’s films may confuse the way children understand death (Cox, 2005), making fantasy and reality difficult to distinguish from each other. Fairytales often involve stories of children who live with stepfamilies after their parents’ deaths and characters who die from eating poisonous fruits or being eaten by monsters (Lee et al., 2009). Conversely, media such as television, movies, printed graphics and those broadcast over the internet may serve as catalysts to introduce the concept of death, opening discussions between children, peers, and adults.
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Partnerships between ill children, their families, and healthcare providers may help support the provision of effective EOL care (Monterosso et al., 2009). Dunlop (2008) recommends the use of creative research methods in PPC such as narratives where children may share stories. It has been argued that qualitative research honours two core considerations when researching childhood issues: individuality (not based on age alone) and balancing seriousness and fun (Carter, 2011). While it may be argued that quantitative research allows for the same issues, qualitative methods may allow for more flexibility in modifying the way data is extracted, such as in the case of semi-structured interviewing. In approaching child participants, the researcher took on the role of an “unusual adult” (Christensen, 2004a, 2004b), interacting with young participants on their level while maintaining a safe psychological distance from them. The unique qualities of child participants steered the approach of this research.

It is commonly believed that qualitative approaches are most appropriate for exploratory research about which little is known. They may help set the groundwork for future studies. Though sometimes criticised by quantitative researchers (Corbin & Strauss, 1990), qualitative research is suited for researching quality of life and allows for flexible data collection methods (Amidi-Nouri, 2008). It is especially useful in situations when participants with individual needs and circumstances are expected to achieve different outcomes (Patton, 2003, p.4). It is highly contextual and allows for the voices of participants to challenge the dominant discourse, using the researcher as the main tool. Qualitative methods were employed for all methods aimed at obtaining the perspectives of PPC patients and those of their family members.

Methods from writings around thematic analysis (TA) and grounded theory (GT) were employed. TA and GT have complementary components. Neither TA nor GT requires one to
be tied to any established theory. Either can be used within several theoretical frameworks (Braun & Clarke, 2006). This makes them appropriate when analysing areas such as communication within families receiving PPC, which fits into the fields of health, developmental, and social psychology. TA and GT are most appropriate because of their utility in creating foundations in new fields and supporting knowledge sharing and communication.

A pragmatic approach was taken in conducting this qualitative research. It was accepted that participants would likely hold many different viewpoints, so reconciling their views through pluralistic means was prioritized highly. Since the subjects of this research were drawn from a very sensitive population, randomly selecting them would be inappropriate. Instead, a slightly purposive sampling method was employed. Families receiving PPC were also not appropriate targets of intervention as few empirically validated suggestions regarding communicating within them have been made. Therefore, clinical teams which oversee potential participants’ care were selected to recruit participants, data were collected through sensitive interviewing techniques, and several steps were taken to prevent bias. This included delivering questions to participants in a semi structured format, careful transcription by the interviewer to ensure the accurate translation of data from spoken to written format, and the use of several intercoders to ensure that the themes arising from the data were impartial.

Grounded theory is appropriate for exploring patterns which arise from the research process during the progression of the research. It does not require the imposition of a theory on the data set, such as in qualitative death research (Reynolds, 2006). The goal of GT is to produce a theory that is grounded in the data (McLeod, 2001), rather than imposing existing theory on new cohorts. The developing theory and themes are continuously checked and modified according to the data collected to ensure that the results are grounded in the
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experiences of research participants (West, 2001). When using GT, the researcher first makes a research inquiry, raises terms to concepts, asks more questions, and clarifies those concepts through writing (Charmaz, 1990). Both the researcher’s and participants’ experiences influence the approach taken to data collection, which may also be shaped by developing and established theories. Economic, cultural, political, legal, and social contexts may be incorporated into GT research (Corbin & Strauss, 1990), as is important in the case of child research. The researcher must analyse using a theory and situation-sensitive approach, so questions may change along the way (Charmaz, 1990). Hypotheses (such as one that children and siblings understand or want to know more about their illnesses and deaths than caregivers think) may be made by the researcher before and during the data collection. The researcher shapes and is shaped by the processes and product, making it a reflexive process relevant to PPC.

Thematic analysis (TA) requires one to progress through a series of stages after all the data have been collected (Braun & Clarke, 2006). The researcher must first read all the data fully; taking notes and marking ideas while transcribing it. After the data are read in their entirety, the researcher labels sections with very specific, basic codes as a step toward creating a thematic map. Next, codes are related to each other and to larger themes. Each theme is then reviewed and, if necessary, combined with other themes or broken into smaller themes. All data are re-read and re-coded. The themes are then defined and renamed. Sub-themes may arise during this process (Braun & Clarke, 2006). Reliability checks are made along the way to verify the accuracy of interpretation. After this process is completed, the researcher may finally begin to tell the story the data provides. Qualitative research seeks access to participants’ holistic experience, acknowledging diversity within and between samples by acknowledging their individuality in the presentation of results.
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This research initially set out with the main goal of interpreting the voices of children. Involving children as participants raises issues of power, voice and representation (Christensen, 2004b). However, obtaining information from children themselves was viewed as the most authentic way with allowance for precautionary measures to minimise the risks. The issue of adult authority may be minimised when the child and researcher are together in a one-on-one situation (Coyne et al., 2009), such as an interview. In order to gather and interpret information about children, researchers attempt to look at their topic of research through the participants’ eyes. For example, the concept of illness (and perhaps death) as taboo or negative develops with age (Christensen, 2004b). Researchers must build rapport with their participants and respect their anonymity and confidentiality. In the context of child participants, it has been suggested that researchers take on the role of “native insider” or adult “friend” (p. 173). Though nurses (common gatekeepers of child participants) might believe children will be negative towards them if they participate in studies, children who participate do not generally display negativity (Coyne et al., 2009).

Fitzgerald (2005) contends that “parents, children, and healthcare professionals who do choose to share their stories [participating in research by divulging the needs of their ill children] are outside of the ‘normal’ realm of social boundaries.” All studies which involve voluntary participants are potentially biased. However, participants may take part because they believe they have crucial information to share. In challenging the dominant discourse and accessing the most direct answers to an exploratory inquiry, three qualitative methods and one quantitative method were used, involving three child and two primary caregiver groups. This pragmatic approach was selected after consultations with many other researchers, clinicians and families.
3.2. Method Precautions, Application, and Further Justification

Exchanges with parents in a bereaved parents’ community message board (Trademe.co.nz, 2010) gathered information which informed this study’s approach. Focus groups were initially proposed for gathering information from caregivers. One could infer from the message board that its members felt some sense of comfort from relating to others that had been through the same sad situation of losing a child.

Death is a tapu, or sacred, subject and the focus of this study. Considering that the researcher is not a native New Zealander, Maori consultation was sought before the research topic was even confirmed, as suggested in the Guidelines for Researchers on Health Research Involving Maori (Health Research Council of New Zealand, 2008). However, it was predicted that the topic was perhaps more comfortable for Maori families to address than Pakeha, considering that Maori children are commonly included and involved in all aspects relating to death and tangi and they often understand and comprehend death through personal experience and exposure to tangi (Jacob, 2011). Nonetheless, a totika Maori research companion was consulted and dialogue continued with Maori throughout the research process (Health Research Council of New Zealand, 2008).

The research process was also guided by the advice of the Northern X Regional Ethics Committee (A+4529, A+4530, A+4531) under delegated authority as well as from the University of Auckland Ethics Committee. An ethical approval report (10 copies of each of the three 50-page reports; a total of 1,500 copied pages) took several months to complete, revise and be accepted for Studies One, Two and Four. Gail Gillies, the Nurse Manager at the Starship Children's Research Centre assisted with this process. The committee sought a personal meeting with the principle investigator (accompanied by a supervisor) to ensure the
proper precautions were taken. Annual progress reports were submitted and approved. Authority was obtained separately from the appropriate managers within the Paediatric Palliative Care Team, Child Cancer Foundation, Heart Children (recently renamed “@Heart”), CanTeen and each individual school at which families were contacted. The University of Auckland Ethics Committee approved the full proposal of Study One within one month.

Families for Studies 1, 2, and 4 were recruited primarily through the Paediatric Palliative Care Team (PPCT) at Starship Children’s Hospital in Auckland. The Starship Children’s Hospital is the largest children’s hospital in New Zealand. It opened in November, 1991 and has since treated over one million patients (Dow, 2005). Children at Starship are supported by several networks. At the centre of Starship is a brightly coloured atrium with a small, musical carousel and pastel glass elevators which may help young patients by providing comfort, socialization, boundaries, and respite from nearby highly medical places (Adams et al., 2010). The hospital seeks to give ill children normalcy through providing programs such as nightly activities run by Radio Lollipop (Radio Lollipop Chair, 2008). As the locality of the only PPC specialist team in New Zealand, it was viewed as the most appropriate location for this research.

The Paediatric Palliative Care Team (PPCT) includes a Specialist Paediatrician, Nurse Specialist, Specialist Paediatric Social Worker, Grief and Bereavement Counsellor, and Child Psychiatrist (Starship Children’s Health & Starship Foundation, 2009). The PPCT was
consulted before, during and after the study was designed. The PPCT members recommended consultants to contact and literature to help with background information about death studies and cultural sensitivity. They were supportive of the research while keeping the safety of the families for whom they cared as their first priority. They were the first friendly set of gatekeepers into accessing families and children.

The PPCT referred families who they saw fit to be involved in the research (for three of the four studies) based on families’ abilities to speak English and the ages of their children (required to be between nine and 22-years-old). Unfortunately, most of the patients under the care of the PPCT during the years in which the study was conducted were families with infant or pre-lingual children who were not eligible to participate. After being notified of the study by the PPCT, each referred family received a phone call from the primary investigator, who sent informational brochures or personally visited them (usually in their homes) to explain the research process and deliver information sheets. They were given a follow up phone call two days to two weeks later. The majority of the families were willing to participate in one or more of the studies after the first meeting and were interviewed or provided with diaries on subsequent visits. The PPCT was contacted approximately monthly via email, phone call or visit to be reminded to continue recruiting families.

A few families initially heard about the studies through the Child Cancer Foundation’s newsletter “Sharing” (Child Cancer Foundation, 2010) (Appendix 2), which goes out to families, donors and sponsors of the organisation. Family Support workers at Heart Children and CanTeen also distributed brochures about the research to families to help with recruitment. Child Cancer Foundation, Heart Children, and CanTeen provide emotional and financial assistance to children and young people with serious medical conditions and their families. They aim to help those in need before, during and after their treatment at the
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hospital (CanTeen, 2010; Child Cancer Foundation, 2010; Heart Children New Zealand Inc, 2010). Participants who learned of the study through the “Sharing” magazine emailed or called the principle investigator directly to establish contact.

School children and their primary caregivers were recruited for the third Study through principals who gave permission to the researcher to send information home with the students. Principals at approximately 96 public and contributing schools were emailed in groups of five to 10 emails to ask about their interest in helping a PPC researcher. Those who responded were met by the principle investigator at their respective schools. Most principals who attended meetings then consented to participate. If willing, the principle investigator met with the teachers to explain the research process during an afterschool meeting or tea break. They were then given study packets to distribute to all the children in each of their classes. It was assumed that they handed the packets out to children within the week they received them and that the children took them home and gave them to their primary caregivers. Only primary caregivers who wished to take part in the research used the Freepost envelopes to return the required information (or “Decline to Participate” forms) to the researcher at the University of Auckland. The principle investigator then travelled to the schools to talk with the children of consenting primary caregivers (students in Years one, two and three) who were told about the study and asked if they would like to assent to being interviewed.

**Study One**

Before caregivers talk to their children about the extent of their illnesses, they generally consider what their children know about health, life and death. It is worth noting that one’s biological understanding of death neglects all other aspects of the event. Dying is a human, social and spiritual experience (Schwass, 2005). This study only focuses on death as a biological event,
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as do many previous studies in the field (Kane, 1975; Lansdown & Benjamin, 1985; Reilly et al., 1983; Slaughter & Griffiths, 2007; Speece & Brent, 1984; White et al., 1978). This study was performed before Study Two because of the additional preparation time required for Study Two (to design the project and to consult with the ethics committee).

In order to assess how mature a child’s death concept is, many researchers have used Hoffman and Strauss’ five concepts of death (Hoffman & Strauss, 1985), adapted from Kane’s (1975) 10 subcomponents. The concepts include defining death as a cessation, the ceasing of all biological and psychological signs of life; a necessity (inevitability), life will end in death; an irreversibility, one cannot return from death to life; attributed to causality, death is caused by biological reasons; and a universality, death occurs to every living thing.

Several tests have been developed based on these concepts and those of Piaget including Loomis’ Concepts of Death Interview (Jay, Green, Johnson, Caldwell, & Nitschke, 1987). The tests generally recognise that primary school children are difficult to engage in lengthy conversations (Rollins, 2005), and so short interview techniques were used. The “standard death interview” assesses the knowledge of five subcomponents of the death concept (Slaughter & Griffiths, 2007). It has been successfully employed in Australasia as a measure of children’s levels of death understanding. The additional question “Do you think that someday you will die?” (Reilly et al., 1983) was added to determine the child’s belief in personal mortality. It is worth noting that the concepts used are not infallible. While the limitation of using single-item scales should be noted, the practicalities of obtaining and retaining the young research participants guided this research. It has also been noted that not all families or cultures explain death as an irreversible event (Shu & Shih-Fen, 2006). However, when comparing primary caregivers’ awareness of their children’s perceptions to children’s actual perceptions, this issue does not limit the study.
Structured interviews were selected for direct comparisons between the large number of children interviewed and their matched primary caregivers who filled them out in a questionnaire format. Though it may be the case that lower levels of self-disclosure of socially undesirable information occur in an interview than a questionnaire condition (Locke & Gilbert, 1995), the impracticality of recruiting primary caregiver participants to come to the school was too great.

Primary caregivers may not be able to determine what their children want. As mentioned, differences exist between what primary caregivers think their healthy children need and the children’s self-reported needs (Monterosso et al., 2009). Perhaps this discrepancy also exists between children’s perceptions and what their caregivers believe they perceive. Assuming the discrepancy exists, it may be due to the taboo nature of death. In a study involving a topic defined by adults as being private, sacred, or stressful, one researcher reported, “The children didn’t seem to think it was a sensitive topic!” (Powell & Smith, 2009, p. 128). One cannot assume that young people are afraid and unaware of death. A three-year-old boy once tried to make conversation by telling an older woman, “You know, we’re all going to die one day” (Rosenburg, 2010). Young people may not view death through the same guarded lenses that adults do, so involving them research may yield results different to those reported by adults.

As a death researcher, I have heard similar stories not only from participants, but friends and colleagues who have heard of my studies. People generally either react with a sense of fear, interest or delayed relief when I introduce them to my work. Often, personal stories of children’s encounters (both their own and those of others) with death are brought up willingly. Many of the teachers at the schools I frequented told me of stories involving death they had heard from the children in their classes. Unfortunately, these were not
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included in the analysis of Study One due to strict adherence to the described study method, though a few are commented on in the discussion.

As with research in any setting, it is important when conducting school-based research to do so in a sensitive manner. One researcher went so far as to propose that schools are already burdened with the responsibility of solving societal problems (Harrell et al., 2000). For this study, the full support of principals was sought before information was sent to caregivers. The researcher assumed full responsibility for contacting caregivers within the school after teachers were informed of the nature of the study. In this way, the type of information caregivers expected their children to know about death as a biological concept was quantitatively compared to what children reported knowing about death.

**Study Two**

Some researchers involved in investigating family issues propose that it is important to give the initial voice to the caregivers as they are whom the research aims to help (Jerram et al., 2005). Primary caregivers are also the gatekeepers whose consent must be obtained before minor participants are contacted (Northern X Regional Ethics Committee A+4530, A+4531). It has been suggested through the use of focus group methods in samples of young people that when used in safe, appropriate environments, questions and probes help participants contribute to research (Peterson-Sweeney, 2005).

Focus groups generally aim to appear non-threatening to participants (Heary & Hennessy, 2002). They allow for the collection of a diverse range of data directly from participants (Peterson-Sweeney, 2005) and have been used to engage with families dealing with children’s health issues (Murray et al., 2007). However, this may not always be feasible in communities with limited resources. Due to scheduling (time and location) constraints and
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a preference for privacy, most parents asked to be interviewed in the privacy of their own homes. Most preferred individual interviews, but participants who were not alone were in groups of two (generally a parent and his or her partner). As a result, data were collected from primary caregivers via interviews rather than the planned focus groups.

Anyone who considered themselves a “primary caregiver” of a PPC patient was invited to participate in Study Two to reflect those most involved in PPC in NZ. Whanau is a constantly evolving term (Metge, 2001). It carries multiple meanings, especially in the changing structure of New Zealand families. There are now smaller families, de-facto marriages, break-ups, solo parents and blended families. Other factors to also consider include longer life expectancies, increased poverty, poor housing and ill health. A whanau is an inclusive group of people who work together to support members and work toward other purposes such as raising children. It may include parents, siblings, extended family, and friends. All whanau members who considered themselves primary caregivers were invited to participate. As a result, not all primary caregivers of the PPC patients and siblings were their biological parents. Interviews were used to obtain primary caregivers’ insights into reasons for speaking about death or avoiding the topic with their children.

Study Three
In order to meet the needs of a child dealing with a terminal illness, it has been suggested that one must work with the child at his or her level of development (Himelstein et al., 2004). Children “talk” through play, art and story-telling. Journal-writing has been suggested as a useful technique for expressing spirituality or questions of faith (Davies et al., 2002). Some have claimed that telling one’s own story and having it heard and honoured has substantial therapeutic benefit, especially in the domain of palliative care. According to one study involving cancer care centre users, face-to-face interviews may be the most acceptable research design and randomised control trials the least favoured (Hepworth, Robertson, Jhunjunwala, Jarvis, & McVittie, 2011). Developmentally appropriate outlets for children (Himelstein et al., 2004) include activities such as picture-drawing and story-writing. Drawing helps children communicate about health issues and express their perceptions and needs (Rollins, 2005). Writing in locked diaries may help children with the expression of emotions, an integral part of supporting children through change and loss (Goldman, 2004).

Young people’s opinions, awareness, and feelings about issues that affect them are infrequently addressed in research. Responses generated by asking patients themselves what is important for them in preparing for the end of life may differ from the things identified as important for them by their families (Steinhauser et al., 2001). Paper is one frequently-used medium for doing this (Rollins, 2005). Professional hardcover sketchbooks communicate the importance of and respect for what will be inside. Combination-locked diaries were provided.
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to participants to give them a sense of privacy. Due to the nature of PPC patients’ illnesses which often contributed to disability, participants were given the option of recording their responses on audio recorders. They were assured that measures would be taken to keep their information confidential in hopes that they would disclose novel information that would be useful for caregivers in the future. PPC patients and their siblings were able to tell their stories by recording them using confidential diaries.

**Study Four**

Many parents of children with serious illnesses agree that “Kids can tell you things a parent can’t.” Some parents of children with genetic conditions stated that interviewing children “may help the parents find out and understand what they know and how they’re dealing with it” (Hadley, Smith, Gallo, Angst, & Knafl, 2008, p. 7). Healthy children express different needs from those expressed by their parents (Monterosso et al., 2009). This difference is likely to be a problem in identifying and meeting the needs of the siblings of PPC patients.

Interviews, though not as rapid as focus groups, provide participants with a sense of confidentiality. They are one of the best methods for complex topics (Heary & Hennessy, 2002). Semi structured interviews were employed to ensure sensitivity when addressing siblings’ perceptions of their needs.

Children may be affected by parental presence during interviews, either by constraining them from telling their opinions freely or by making them feel more relaxed and comfortable in the formal interview setting (Coyne et al., 2009). Therefore, individual, private interviews with the children were sought. Stipulations specified by the primary caregivers were respected and a child-oriented environment was provided as recommended.
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by caregivers (Hadley et al., 2008). Each young participant’s preferred interview location was always sought, whether outside of their home or in a private room in their home.

A child-centred approach was engaged for this study. Siblings of cancer patients two years after diagnosis expressed concerns about their own positions in their families (Houtzager et al., 2004). This study emphasised the importance of the sibling’s self-report. Though they may want to protect them, caregivers were not allowed to speak for siblings.

The interview questions integrate aspects of siblinghood outlined in “Guidelines for Addressing Spirituality in Siblings” (Davies et al., 2002, p. 63) as well as those from various other studies (Alderfer et al., 2009; Bluebond-Langner, 2000; Packman, Horsley, Davies, & Kramer, 2006; Spinetta et al., 1999). One question asked about children’s feelings at the time of diagnosis. This time signifies a solid line of “before and after” (Sourkes, 2007, p. 38), the divide between normalcy and unpredictability. The semi-structured format of the interviews allowed the children the ability to be guided further into topics the researcher perceived children held to be more important.
Chapter 4. STUDY ONE—CAREGIVERS’ PERCEPTIONS OF CHILDREN’S UNDERSTANDING OF DEATH

4.1. Abstract of Study One

Communication about death is often a sensitive topic in families with children. The present study compared answers given by 141 primary school children aged 5-7 to questions about death, and their caregivers’ predictions of how they would answer. Children were interviewed and caregivers responded on paper using the *Children’s Understanding of the Human Lifecycle Interview*, which defines death in terms of inevitability, applicability, irreversibility, cessation, causation and personal mortality. For causation, cessation and irreversibility, children were significantly more correct than caregivers expected, and the difference between girls’ and their caregivers’ scores of applicability was more pronounced. Communicating with children about death may not always be as caregivers expect.

4.2. Literature Review of Children vs. Caregiver Death Perceptions

Talking about death is not easy. As one Health Care Provider (HCP) writes, “Children are not comfortable with dying and providers are not comfortable with dying children. Losing the child is a big deal for the physicians, the nurses, and for the family. So it’s not an easy thing to talk about. The dialogue for death needs to happen a lot sooner than the moment of crisis” (Bearison, 2006, p. 153).

What caregivers know about children’s understanding of death is likely to affect the way they speak about it with their children. The impending death of a family member, friend or other may be a topic caregivers generally do not wish to discuss with children. However,
most paediatric health care providers and palliative care specialists generally advise caregivers to be open and honest with children to maintain trust and address their fears (Hilden et al., 2000).

There may be discrepancies between the knowledge children hold about terminal illnesses and the knowledge that their caregivers believe they hold. Such discrepancies may cause caregivers to hide information from their children. In a survey of bereaved children who were given the opportunity to ask questions to a doctor, the largest category of questions identified was 52% relating to the cause of death (Thompson & Payne, 2000). This suggests that children frequently may be left out of conversations on death-related subjects. Some research supports the practice of including children facing the end of life in decisions about their care (Faulkner, 2009; Hilden et al., 2000). Most English-speaking countries, including New Zealand, encourage an inclusive approach. For example, the Starship Children’s Hospital Paediatric Palliative Care team in Auckland, New Zealand (Starship PPCT, 2009) encourages open communication within the families they treat and recognizes a need for courageous advocacy on behalf of children and families.

However, many people still believe that children under 10 years of age who are dying are unaware that they are dying, so adults should not answer their questions about death (Himelstein et al., 2004). Some caregivers may believe that sheltering children from the knowledge of impending death will protect their children’s innocence from pain and suffering. However, children will inevitably be exposed to death in play, the media, or through personal experiences.

One’s appreciation of approaching death is believed to develop with age and cognitive ability (Bauer, 1976; Shu & Shih-Fen, 2006). A child’s understanding of the simple
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Subcomponents of death are believed to precede complex ones: universality precedes irreversibility, causality and cessation, which precede inevitability (Hoffman & Strauss, 1985). Though sequential age/ stage theories of death have been proposed, other researchers suggest that understanding does not happen in a predictable developmental sequence (Speece & Brent, 1984). Regardless, cognitive maturation and age are associated with fuller death understanding.

A study of bereaved caregivers (Kreicbergs, 2004) whose children had died of cancer between 1992 and 1997 asked the caregivers whether they had talked about death with their child and if so whether they regretted having that conversation. Of the 147 (34%) caregivers who talked about death with their child, none regretted it. However, of the responsive 258 (66%) caregivers who did not talk with their children about death, 69 caregivers (27%) regretted not having that conversation. Caregivers who believed their children were aware of their impending deaths more often regretted not having talked about death with their children. Caregivers who did not sense the awareness of death in their child were less likely to regret not talking to them about it.

Further, caregivers with older children were more likely to regret not discussing death with their children (Kreicbergs, 2004). This finding may be due to caregivers’ knowledge that their children were aware that they were dying. Among caregivers of children between the ages of 5 and 8, 22% regretted not talking about death. Several studies cite ages 5-7 as the major transition period for change in children’s understandings of death (Lansdown & Benjamin, 1985; Reilly et al., 1983; Slaughter & Griffiths, 2007). Therefore, ages 5-7 may also be a time when caregivers underestimate their children’s understanding.
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For effective communication between caregivers and children, it is important for caregivers to have an accurate understanding of their children’s existing level of knowledge about the topic. Disparities between caregivers’ understanding and children’s knowledge could lead to confusion. There appear to be no empirical studies that compare children’s knowledge about death to their caregivers’ understanding of their knowledge. The present study was therefore conducted in order to provide an initial assessment of how the two compare. The child’s age, gender and ethnicity were explored as contextual factors having the potential to influence the relationship.

4.3. Study One: Children vs. Caregiver Death Perceptions Method/ Theory

4.3.1. Study One Materials

The Children’s Understanding of the Human Lifecycle Interview (CUHLI) was devised by the authors specifically for this study (Appendix 3). It drew heavily from the Standard Death Interview (SDI) (Gerald P. Koocher, 1973), which assesses knowledge of five subcomponents of the death concept. A question to assess children’s belief in personal mortality (Reilly et al., 1983) was added. The SDI questions and scoring guide are frequently used to assess four to 10 year old children’s understanding of death concepts (Slaughter & Griffiths, 2007). In previous studies of pre-schoolers, test–retest reliability for the interview was .61 over two weeks (Slaughter & Lyons, 2002). Caregivers’ and children’s responses to the questions assessing inevitability, applicability, irreversibility, cessation and causation were scored according to the guide outlined by Slaughter and Griffiths (2007), whereby each answer was given a score of 0 (biologically incorrect), 1 (partially correct), or 2 (biologically correct) (Appendix 4). The final question assessing personal mortality was similarly scored.
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The caregivers’ and children’s subcomponent scores were combined to yield a total score out of 12.

In the present study, the CUHLI showed low internal consistency ($\alpha = .47$ for caregivers, .47 for children). Therefore, scores were analysed individually.

An anonymous “Decline to Participate” form was included in envelopes sent to caregivers (Appendix 5). It asked caregivers who chose not to participate why they chose to opt out. Blank lines were provided next to boxes which they could tick to categorize their answers nonparticipation as the result of “Personal,” “Cultural,” “Religious,” or “Other” reasons.

4.3.2. Study One Procedure

The researcher sent personalized emails to 97 principals. After meetings with the 15 principals who responded to the emails (which were followed up with phone calls), 12 of them chose to take part (two schools were later eliminated because two or fewer caregivers responded at each of them). Principals were provided with information sheets (Appendix 6) and those who agreed signed consent forms (Appendix 7). Next, the researcher met with teachers at each school to explain the rationale and procedure and give them information sheets (Appendix 8) and consent forms (Appendix 9) similar to those given to principals. Two principals requested that this step be skipped due to teachers’ busy workloads. To recruit a diverse sample of participants, each consenting school received questionnaires for all primary caregivers of students in years 1, 2, and 3 (usually at the teacher meetings). Each packet included an information sheet explaining the study (Appendix 10), a consent form (Appendix 11), a decline to participate (DTP) form (Appendix 5), and a CUHLI (Appendix 3).
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with a freepost envelope. Most principals also wrote a brief statement to caregivers explaining their rationale for allowing their participation (Appendix 12).

Thus, caregivers completed in writing a CUHLI and children of consenting parents completed a CULHI orally during school time. Only children of caregivers who completed the CUHLI and signed consent forms were asked if they would like to participate. All of these children, when invited, agreed to participate by signing assent forms (Appendix 13). The decline to participate form asked non-participants why they chose not to take part.

Responses given on posted questionnaires may be more positively skewed than responses gathered through interviews (Trozer, 2000). If that is the case, then one might expect primary caregivers’ (written) answers to be likely to overestimate their children’s (spoken) responses to the CUHLI questions. For the sake of caregivers’ time and university and school resources, questionnaires were the most feasible way to gather responses from primary caregivers. In order to increase primary caregiver return rates, participant information sheets, consent forms, and questionnaires were given out in freepost (postage paid) envelopes; the easiest questions were given first in the questionnaires; the questionnaire length was kept to a minimum; and cover letters including appeals (Viljoen & Wolpert, 2002) from primary school principals were folded around participant packets. In some cases, principals gave prior notification of the study in newsletters to parents.

Following the completion of the interview, each child was given a debriefing form (Appendix 14) to take home to their primary caregiver. The letter included the principal investigator’s contact information, should any issues arise following the study. Participants were informed that counsellors would be available on request to families.
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Once the parents sent in their children’s forms and the children were interviewed, the responses were scored according to a modified version of the scoring guide used to score the “Standard Death Interview” (Slaughter & Griffiths, 2007, p. 529) (Appendix 4). For question 8 of the final subcomponent personal mortality (“Can you tell me something that might happen that would make someone die? ...When [the children’s answer] happens, why does that person really die?”), children received a score of 0 points for giving an external cause of death (e.g. ‘knife because they are bad’), 1 point for referring to the body (e.g. “because they are hurt really badly”), and zero points for giving a fully explicit, biological answer (e.g. “they stop breathing,” “blood comes out,” “heart/breathing/brain stops”).

**Study One Analysis**

Visual analyses were examined first to give an overall impression of the study outputs. Given that the data involved considerable clustering (both by dyad and by school), for those variables in which none of the explanatory variables could be shown to be related to the outcome, a generalised mixed model was used with the score for the question coded as two or less than two (i.e. reduced to a binary variable) and the child and caregiver score as a repeated outcome. A score of two was coded as entirely correct (Appendix 4) and a non-two was coded as at least partially incorrect. School was included as a random effect and group (child or caregiver) as the explanatory variable.

Ethnicity, school decile, age and gender were explored as contextual variables before the main analysis was conducted. In an attempt to investigate factors that could be associated with differences in the child’s perception and what the caregiver believed was their child’s perception, a generalized mixed model was used with the difference in the score of each child
and caregiver (child score-caregiver score) as the ordinal outcome and school included as a random effect to allow for within school correlation.

4.3.3. Study One Participants

141 sets of primary caregivers and their children in years one to three from co-educational, state-funded full primary and contributing schools were invited to participate. Single-sex, integrated, and independent schools were excluded from the study in order to avoid clusters of philosophical or religious beliefs, as have been proposed as affecting death perceptions (Valentine, 2007). Caregivers of children at 10 schools participated in the study. Parents of children at three lower decile schools (deciles 1, 2 and 3) were also invited to participate, but no forms were returned by the caregivers from those schools. Principals attributed the poor response rate primarily to language barriers. Unfortunately, this resulted in a group of participants from higher decile schools (4-10).

Caregiver-child pairs were recruited from 10 primary schools in Auckland, New Zealand between September 2009 and June 2010. Participant packs were given to students in years 1, 2, and 3 at schools where principals and teachers granted the researcher permission to contact students’ families. All schools were state, co-educational, primary schools. Though a range of economic and social strata was sought, schools ranged in decile from 4 to 10 ($M = 8.06$, $SD = 2.29$). 39.7% of children interviewed were from (2) decile 10 schools, 27% of children interviewed were from (3) decile 9 schools, 16.3% of children interviewed were from (2) decile 6 schools and 17% of children interviewed were from (3) decile 4 schools. Thus, most were in upper to middle-class areas.

According to caregivers’ responses, ethnicities included: 54.6% European, 9.2% Māori, 5.7% Pacific Islander, and 30.5% other. In the European category were those who
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defined their ethnicities as New Zealand European, Pakeha, White, Caucasian, British, Dutch, Other European, or South African European.

The children (77 boys, 66 girls) were 5, 6 or 7 years old. Of 1,722 eligible participants, 141 (8%) responded. Of the respondents, 24.8% were five-years-old, 42.6% were six-years-old and 32.6% were seven-years-old ($M = 6.08, SD = 0.76$).

4.4. Study One Results

A visual analysis comparing child and primary caregiver scores shows children scoring an average of approximately one point ($M = 0.97, SD = 1.91$) higher than their matched caregivers on total CUHLI scores, not taking any other variables into account (Appendix 15). This was evidenced on a graph comparing matched caregiver and child total scores from the first two schools tested (Appendix 16).

Several simple tests were run to assess roughly the raw data before running more complex analyses. A bivariate analysis was conducted in order to understand the differences between the two variables (children and primary caregivers) and whether these differences are likely to have occurred by chance alone. A parametric test was run first because it was assumed that the data were mostly normally distributed (though this was not necessarily the case). A two-tailed Paired-samples t-test of the difference (Appendix 17) revealed a low Pearson Correlation Coefficient $r = 0.399, n = 140, p < 0.01, 99\% CI [0.54, 5.99]$.

The individual subcomponent scores were considered next. Graphs comparing the raw scores of primary caregivers and children on each subcomponent were constructed (Appendices 18, 19). The next step in preliminary analysis taken was conducting a one-way
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ANOVA to compare the effect of caregiver scores on each of the subcomponents of death. There was a significant effect of the caregiver score for inevitability on the child score for inevitability at the \( p < .00 \) level \([F(12, 12) = 3.879, 4.043, p < .01]\). There was a significant effect of the caregiver score for applicability on the child score for applicability at the \( p < .01 \) level \([F(12, 12) = 2.304, 4.071, p = .011]\). There was a significant effect of the caregiver score for irreversibility on the child score for irreversibility at the \( p < .00 \) level \([F(12, 12) = 5.958, 5.608 p = .000]\). There was a significant effect of the caregiver score for cessation on the child score for cessation at the \( p < .00 \) level \([F(12, 12) = 2.513, 2.781 p = .005]\). There was no significant effect of the caregiver score for causation on the child score for causation at the \( p < .05 \) level \([F(12, 12) = 1.415, 1.572 p = .167]\). However, there was a significant effect of the caregiver score for personal mortality on the child score for mortality at the \( p < .00 \) level \([F(12, 12) = 2.792, 2.820 p = .002]\).

Taken together, these rough preliminary results suggest that caregivers do not have an entirely accurate understanding of their children’s awareness of death as a biological concept. Specifically, the results suggest that caregivers consistently underestimate how their children will respond to questions about applicability, irreversibility, inevitability, cessation and personal mortality.

Most children were correct in their understanding of biological death with all children answering at least half the questions correctly. Each of the six dimensions was assessed for significance of the differences in scores, with a Bonferroni correction indicating a significance threshold of 0.083 rather than the conventional 0.05.

There was no evidence of a significant difference between child and caregiver scores for inevitability \( F(1,140) = 1.0, p = .32, \ OR = 1.3, 95\% \ CI [0.78, 2.3] \). However, children’s results differed significantly from their caregivers’ on scores of causation \( F(1,140) = 53.6, \)
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$p < .001$, $OR = 6.0$, 95% CI [3.7, 9.8], irreversibility $F(1,140) = 5.6$, $p = .02$ $OR = 1.9$, 95% CI [1.1, 3.4], and cessation $F(1,140) = 4.9$, $p = .03$, $OR = 1.7$, 95% CI [1.1, 2.8]. Applicability and personal mortality were not included because other factors may influence those variables. There is some debate as to the appropriateness of correcting for multiple comparisons in a study of this nature (Bender & Lange, 1998; Perneger, 1998), and it should be noticed that a Bonferroni correction taking into account three comparisons would indicate a significance criterion of $p < .017$, leaving causation as the only factor to show a significant difference.

For applicability, the mean difference between child and caregiver was statistically significant. The amount that the child score exceeded the caregiver score was significantly greater in girls than in boys $F(1,130) = 6.51$, $p = .01$. Girl children tended to have higher scores than caregivers.

Initial analysis indicated that differences in primary caregiver / child scores for applicability and personal mortality were influenced by children’s gender and ethnicity. For applicability, the mean difference between child and caregiver was related to gender. The amount that the child score exceeded the caregiver score was greater in girls than in boys, $F(1,130) = 6.51$, $p = .01$, $OR = 2.5$. Girl children had significantly more right answers ($M = 1.81$) than caregivers ($M = 1.48$).

The only remaining variable to be significantly associated with the child/caregiver difference was ethnicity. Pacific Islander children were less likely than other groups to have higher scores than caregivers on personal mortality, $F(1,130) = 3.19$, $p < .03$. The eight caregivers who identified as Pacific Islander were more correct ($M = 2$) about their children’s understanding of personal mortality ($M = 1.37$) than other caregivers ($M = 1.63$) about their children ($M = 1.82$), suggesting that Pacific Island caregivers were better able to predict their
children’s level and knowledge of death concepts. This should, however, be interpreted with caution due to the small Pacific Island sample (n = 8). Age, and school decile were not significantly associated with the other four outcomes.

Most children were correct in their understanding of biological death with all children answering at least half the questions correctly. As with the subcomponent analyses, a Bonferroni correction was applied to allow for there being four comparisons (inevitability, irreversibility, cessation and causation), giving a revised threshold for significance of 0.0125.

Children’s results differed significantly from their caregivers’ on irreversibility, $F(1,140) = 5.6, p = .02, OR = 1.9, 95\% \text{ CI} [1.1, 3.4]$; cessation $F(1,140) = 4.9, p = .03, OR = 1.7, 95\% \text{ CI} [1.1, 2.8]$ and causation, $F(1,140) = 53.6, p < .0001, OR = 6.0, 95\% \text{ CI} [3.7, 9.8]$ with children scoring higher (more right answers) than caregivers on each subcomponent. Child and caregivers were not significantly different on inevitability, $F(1,140) = 1.0, p = .32, OR = 1.3, 95\% \text{ CI} [0.78, 2.3]$.

Many caregivers did not wish to participate for various reasons (Appendix 20). According to the 42 caregivers who returned DTP forms, these included personal (79%), cultural (21%), religious (21%) and other (26%) reasons. Personal reasons included not wanting to discuss death outside the family: “We discuss death in the context of my father dying and we miss him, as well as animals. I don’t wish my five-year-old to discuss death with strangers. He and I were both with my father when he died in hospice” (NZ European), age-appropriateness, children being particularly sensitive to or upset by death:

I’m sorry but we think that it is an inappropriate topic for her at this age. [My child] recently had a relative pass away and when we discussed with her what happened, she became very distressed with the thought that she may die one day and it has taken
some time to eventually stop raising the topic, so for her, personally I and her father would prefer not to raise questions of this type with her again just yet. I hope this explanation has been of some help. (European; emphasis added)

Primary caregivers also worried about overburdening children with information: “My boy is only 5 years old. A topic that I don’t want to discuss in detail with my son because they are only little and have limited understanding/mental capacity. I don’t think we need to discuss it with 5 year olds, maybe feel more comfortable when they are 7 or 8” (NZ European).

If our son asks us questions Re: death & dying, although it is hard, we do our best to answer him, so that he has an understanding, but ‘dying’ is never something that invokes a ‘happy ending,’ so our son would be quite distressed, he tends to react quite intensely to any situation. Therefore I fear that questions asked of him Re: death would cause him too much unsettling. I apologise, but I respect your need for the Research, and wish you all the best. (multiple ethnicities; emphasis added)

My son knows a little about death as his godfather died when he was very young—but, as he is fine, we would not talk to him about death and then not be there to monitor his response. We are concerned that in this study: 1. It is a “stranger” talking to him. 2. He will not be with one of his family after having a discussion about death. Thank you. (NZ European)

Their personal reasons also included planning to move away from New Zealand: “I plan to move with my child away from NZ within the next five years” (Maori).
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Cultural reasons included having already explained death to children and having a different cultural view of death (Māori) and all things leading up to it: “I have already explained this to my children as they have already been to 3 funerals” (Cook Island / Tongan)

“Maori have a different belief in death and all things leading up to it.” (Māori)

Religious reasons included having different beliefs to the mainstream and having already taught their children about life and death “as Christians.”: “As a Buddhist we believe differently to Christian.” (Thai/European)

“As a Christian, they have been taught life & death.” (Cook Island / Tongan)

Other reasons included the wording of certain questions, a child having experienced an especially high number of deaths in the family, learning difficulties, emotional sensitivity, unpreparedness, and wanting to protect the child’s innocence. Some were not in favour of the approach taken by the researcher:

I don’t like the wording in question 5. As a 10-year-old, I was terrified that people were mistaken and my grandfather was not actually dead and therefore was cremated alive. I don’t want my child to have any concerns about his poppa who has died. (NZ European)

“Too many deaths (of family and friends) in early childhood. Unbalanced influence on child, awareness/ concern regarding topic” (European).

“Daughter has some learning difficulties and explaining this concept would be out of her reach at this point in time” (NZ European).

Our son has a reasonable understanding of the lifecycle and we have talked about death with both our kids. He knows everything dies and that there are many reasons for death. However, he is a deep thinking boy and sensitive to others feelings and we felt that the
seriousness of this session would cause him grief. If it were a general ‘chat’ over a muffin with other people around he’d be fine but this would get him wondering if he or someone close to him is going to die soon. (NZ/ European)

My husband was concerned about question 8. He didn’t think our children had encountered much to prepare them for thoughts that it might trigger. I have however already explained to the children that everything alive dies—sooner or later—. My husband was surprised by this and we decided to decline the questionnaire. Best luck. (European)

“This may affect her emotion” (Filipino).

Several of these caregivers expressed their respect for the “need for the research” and apologised for not feeling able to participate.

4.5. Study One Discussion

The subcomponent most markedly predicted wrongly was causation. Caregivers may believe that children easily worry about how and why deaths occur, attributing them to false occurrences such as “being bad,” for reasons often illustrated in children’s animations (Cox, 2005). False attributions made by children may be dispelled by explanations from caregivers. Those who participated in this study appeared to have a mature understanding despite misleading influences reported in some other studies.

On every dimension, the caregivers tended in general to underestimate children’s knowledge, though the difference was only significant in the case of Causality. One may hypothesize that caregivers would be more likely to predict accurately their children’s
understandings of earlier-developing concepts than later-developing concepts. Applicability is one of the first proposed concepts of death to develop, preceding universality and irreversibility, causality and cessation (Hoffman & Strauss, 1985). However, these subcomponents are all proposed to precede inevitability, which was more accurately predicted by caregivers. The only two concepts that were not underestimated by caregivers relate to living things that die and non-living things that do not die. Caregivers may be more likely to communicate about this sort of information with their children. Communicating about causes of death may be considered more taboo by caregivers.

Children who were interviewed generally knew that they would die someday. The topic of death is not foreign to most children, despite some caregivers’ predictions. They also tended to understand death as a cessation of life which cannot be undone, perhaps indicating that comments like, “Doggy went to sleep” after the death of a pet may not be detrimental to their understanding.

Children may actually understand the biological subcomponents of death outlined before their caregivers are aware that they do. Children generally know they can die and will die. Caregivers, therefore, may have one less reason to shy away from talking about death-related events with their primary school-aged children. This is consistent with most specialists’ recommendations (Faulkner, 1997; Skeen & Webster, 2004).

Though very tentative, this research may be of relevance to families dealing with palliative care when caregivers are deciding whether or not to open discussions about their child’s impending death. It may imply that communication about death may be different (and perhaps even easier) than caregivers think it will be. Increased understanding of death correlates negatively with fear of death in four to eight-year-old children (Slaughter & Griffiths, 2007) and caregivers who believe their children are aware of their impending
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deaths more often regret not talking about death with their children than caregivers who do not sense the awareness of death in their children (Kreicbergs, 2004). Young people with life-threatening illnesses may progress in acquiring a mature understanding of death long before their healthy peers (Freyer, 2004; Masera et al., 1999). Therefore, it may be the case that children are more prepared for discussions of death than their caregivers believe they are and death is a topic families may speak about more openly than they thought was appropriate.

This quantitative study supports and furthers more qualitative work done in the field of children’s end of life care. The literature concerning communication about death with children is severely limited. Children themselves have often asked about dying, yet caregivers have often refused to discuss death with them (Bluebond-Langner, 1978). They may feel that the fear of death is the only thing that they, as caregivers, may protect their children from. However, this study in conjunction with others may imply that keeping death a “secret” may be in vain.

Understanding caregivers’ behaviour when communicating about death with their children requires understanding of the factors underlying their decisions about what to discuss. Some caregivers may not talk about death with their children because they believe their children are not as fully aware of the concept of death as they are in actuality. Caregivers often underestimate how much their children know about death, implying that communication at the end of life may be different than caregivers expect.

Limitations

This study is limited by several factors. In order to maintain high ethical standards, sensitivity to participant needs took precedence over scientific inquiry in this study, resulting in a non-random sample. Participation by caregivers and children was entirely voluntary.
The study was constrained by the honesty of the primary caregivers and children. The caregivers were requested not to inform the child of any related material until after they were interviewed. However, the focus of this study is provocative and may have elicited conversations between caregivers and children relating to death before the caregivers predicted their children’s responses. Likewise, the interviewer attempted to remain as neutral as possible, so as not to elicit predicted responses from the children.

Alternatively, this research could be done by interviewing both caregivers and children. Due to caregivers’ commonly cited time constraints, however, having adults fill out the interviews in writing was considered more appropriate. Doing so allows caregivers greater flexibility in the time they take to complete the study, more time to reflect on the study and to decide if they really want their child to participate, and a clearer understanding of what exactly their child will experience. On the other hand, interviewing caregivers would have given participants the opportunity to meet the principal investigator, perhaps making them more or less likely to allow their children to participate. In a pilot study, caregivers’ written responses to the CUHLI (taken as a survey) were compared to caregivers’ oral responses to the CUHLI (taken as an interview) in relation to their children’s oral responses to ensure internal validity. The internal consistency of the CUHLI itself was not high, with a consequent high risk of Type II (incorrectly failing to reject the null hypothesis) error in statistical analyses.

Participating children and caregivers could also be administered matching surveys. However, the reading and writing abilities of five to seven-year-olds is very limited and young participants may not understand the questions asked of them in writing or be able to answer them in writing.
The collection of ethnicity information was also methodologically imperfect. Caregivers were given a blank line on which to define their ethnicity. Their responses were then filtered into the categories defined in the “Participants” section. The category “Other” may have included participants (such as those who labelled themselves as “South African” or “New Zealander”) who would have placed themselves into the “European,” “Maori,” or “Pacific Island” categories if provided more detailed directions.

Though this study provides some insight into the minds of healthy children and their caregivers, it is not a substitute for more direct, qualitative data from terminally ill children and their caregivers. Studies of death understanding in children of various ages and illnesses may also be useful to caregivers and health care providers.
Chapter 5. STUDY TWO—PERCEPTIONS OF FAMILIES/WHANAU RECEIVING PPC

5.1. Abstract of Study Two

Considering the interconnectedness of relationships within families receiving PPC, “Study Two” set out to explore how primary caregivers experience living with children who have life-limiting illnesses and communicate (or avoid communicating) with their ill and well children around topics related to their impending deaths.

A qualitative study of caregivers’ communication with their children aged three to 22 was conducted using semi-structured, in-depth interviews. Nineteen caregivers living in the Auckland area answered the interview questions which focused on the topic of whether or not to talk with children about their (and their brother’s or sister’s) illness and possible impending death. Extra topics which arose from the interviews were transcribed and analysed as well as those relating to communicating about mortality.

Inductive thematic analysis (Braun & Clarke, 2006) revealed caregivers’ reasons for communicating with their children about death were associated with preparing children while caregivers’ avoidance of the topic related to attempts to protect children. Reasons for speaking with children about their mortality revealed three themes: acknowledging, enabling and teaching. Reasons for avoiding the topic centred on protecting relationships, emotions and perceptions. A second analysis of topics not related to communication about prognosis raised during the interviews revealed that caregivers were concerned about more than the researcher questioned them about (communicating with their children about death). Other themes which arose spontaneously from the data related to the assistance of professional
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organizations and medics, the support of family members, the internet as a research tool, regrets, parental roles and discrimination on the basis of disability.

5.2. Literature Review of Opinions of Whanau receiving PPC

Though adult end of life care has been widely researched, PPC has been less explored. PPC patients’ needs may differ from adult palliative patients; for example, children may live longer than a year after initiating PPC (Feudtner et al., 2011), whereas adults are less likely to outlive their diagnoses by as much time. The effects of learning of, experiencing and processing children’s deaths are rarely talked about, yet children’s dying processes clearly affect children and their families. How children die directly influences caregivers’ abilities to continue their role functions and lives (Hinds, Schum et al., 2005) with up to one-third of bereaved parents reporting marital distress.

Primary caregivers play a vital role in the lives of their ill and well children. Family-centred care, which helps patients and families cope and help each other (Seiber, 2005), is the dominant method used by the medical community to support PPC patients. The most influential relationships in most patients’ lives are those with family members. Considering that PPC patients’ diseases are likely to be primarily managed in the home where intimate relationships develop and family members influence each other’s behaviour, siblings are likely essential members of PPC support.

The death of a child is arguably the most devastating and life-defining event a caregiver may experience (Coleman & Richmond, 2009). Parents, caregivers, and families/whanau of children with terminal illnesses may experience feelings of pain, panic, failure, anguish, and
helplessness both before (Kane & Primomo, 2001) and resulting from (Irving & Thompson, 2006) a child’s death. They may have difficulty feeling that they are accomplishing their role as the protectors of their children, putting their self-esteem at risk (Kane & Primomo, 2001). Caregivers’ perceptions of their children’s illnesses may be guided by their hopes for a cure. Reinforcement theory (Hull, 1943) asserts that people prefer information that supports their current beliefs and attitudes. This may make caregivers less willing to accept a child’s terminal illness, and thus less likely to communicate about it. It is a given, though, that the anticipation of stress and pain comes with caring for a severely ill child is a fair price to pay for maintaining their quality of life (QoL). Some parents feel that allowing their children to feel love counteracts the resulting anguish (Thiele, 2011).

Caregivers use a variety of methods to cope with stressors associated with caring for a terminally ill child. Spiritual issues may be heightened when a child is receiving PPC (Liben et al., 2008). When asked what helped them most during their children’s last phases of life, 73 percent of parents interviewed in a study in Boston mentioned spirituality or religion. Some spoke about maintaining a relationship with their child which transcended the child’s death. Spirituality, religion or life philosophy often helps parents of children with life-limiting illnesses deal with tough times (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). Some parents report that praying and/or reading the bible influence the way they view their child’s medical situations and decision-making around it as well. Many caregivers draw from resources related to spirituality when caring for PPC patients and their siblings.

Communication is central to the provision of PPC (Field & Behrman, 2003). The transmission of information within the family about the child’s health is influenced by the amount of information that each member knows. Information sharing between caregivers and healthcare providers is the most obvious route through which older members of the family
receive information about the child’s illness. Many parents in the USA are likely to receive information first from physicians, nurses, social workers, chaplains, interpreters, or other parents (Davies, Contro, Larson, & Widger, 2010). When HCPs disseminate information through using less than optimal communication styles, frustration, anger, and sadness may result. The ability to understand the language and terms used is essential to effective communication. Caregivers of ethnic minorities in the USA who were not given information about their child’s illness described feeling alone, lost, and “in the dark” in one study (Davies et al., 2010). Participating parents reported that HCPs who provided them with basic information about their children’s diseases and the implications thereof and paid attention to their questions and emotions made parents feel more confident and less distressed in comparison with parents who did not receive the same care. It may not be assumed that caregivers lose hope from receiving prognostic information. Hope for a child’s survival may be maintained by primary caregivers alongside that for pain relief in PPC (Hinds, Schum et al., 2005). Caregivers need to listen and to be informed.

Despite preferring to be informed of the details of a child’s health status, there are many reasons why families might choose to hide information from certain family members (Afifi & Olson, 2005). Social exchange theory proposes that how much individuals influence each other depends on their ability to regulate the types of rewards and costs that others receive (Blau, 1964; Thibaut & Kelley, 1959 as cited in Afifi & Olson, 2005). For example, parents must affirm power over their children to parent assertively (Afifi & Olson, 2005). People are granted power when others perceive that they hold power. In families with children with terminal illnesses, parents cannot control their diseases or protect their children from the symptoms or painful treatments. The power caregivers used to hold may be absorbed by demanding and often unpredictable illnesses. Caregivers may worry about the
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loss of protective power over their children. Instead of shielding their children from physical discomfort, they may see their only role as protectors from psychological trauma. Adults caring for PPC patients may still seek to fill the roles of life supporters of their children in literal terms and in other (emotional, spiritual or other) ways. They may see hiding information from children as a way of helping the children to cope.

The nature of a secret influences whether or not families choose to reveal it (Afifi & Olson, 2005). Family members with negatively-perceived secrets may feel concerned that revealing them will influence the way others relate to them. The more identity-threatening and personal a secret is, the more they may want to keep it a secret. A child’s impending death threatens his or her caregiver’s ability to “take care of” the child and is extremely personal and negatively-perceived. One parent in an American study of families receiving PPC at George Mark Children’s House (GMCH), a children’s hospice, reported “I wanted to care for my son. I’m not giving up on that” (Amidi-Nouri, 2008, p. 137). A grandmother in the same study, praising GMCH, admitted “They even have the suction equipment behind pictures in the wall... What more can you do for a child than to keep that stuff hidden away from them—to—to keep them from being afraid” (pp. 158-159). In regulating the amount of information that children receive by concealing information, primary caregivers support social exchange theory.

Despite HCPs’ family-centred approach, researchers of PPC generally collect data from medical personnel, nurses and occasionally doctors, even for studies of children’s spirituality (Davies et al., 2002; McPherson & Thorne, 2000). Unfortunately, health professionals may conflate their own opinions with those of the children or have only cared for them for a brief period of their end of life (EoL) processes. Families may be depersonalized as a result of medical training or because, according to one doctor, empathising makes the situation more
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draining (Browning et al., 2007). Though valuable, current studies may be inconsistent with the approaches and goals of HCPs. PPC literature lacks studies of the perspective of families involved (Amidi-Nouri, 2008).

What is it like to care for children receiving PPC? What do caregivers and their families value and wish to express to a researcher and those who read the literature in this area?

Generally, a child’s impending death is a topic caregivers do not wish to discuss, especially when it relates to their own child’s mortality. Such reluctance to discuss the impending death may reflect a number of factors (Kane & Primomo, 2001). If there is uncertainty regarding the trajectory of the illness caregivers may find it difficult to judge the timing of any such discussions, making procrastination likely.

Children may want a different amount of information than their caregivers wish to share with them (Stillion & Papadatou, 2002). One study found that 19 percent of families with terminally ill children acknowledged the child’s impending death to them (Goldman & Christie, 1993). Most families avoided the discussion, believing that children were not aware of their circumstances or because they did not know how their children felt or what they knew. Many parents believe that children cannot understand the magnitude of their illness and are better off spared the burden of such knowledge (Skeen & Webster, 2004). However, keeping children’s diagnosis from them may result in isolation, distrust, distress or poor psychosocial adjustment (Rosner, Kruse, & Hagl; Skeen & Webster, 2004; Smith, Perrin, Dyregrov, & Yule, 2003). The consequences of communicating with PPC patients and their siblings may be vast, making investigation worthwhile.

Despite many caregivers’ beliefs, communicating with children about their impending
death or that of siblings may actually decrease these issues (Hilden et al., 2000). PPC specialists generally advise parents to be cautiously honest at the end of a child’s life so that trust is maintained and fears may be addressed (Skeen & Webster, 2004). Though children are not little adults, many of their needs are likely to be similar. Terminally ill (adult) focus group participants expressed that “If one has more time to prepare for death then they have more control over whether their own death is good or bad” (Steinhauser et al., 2001, p. 730). One cannot prepare without knowing what they are preparing for. Doctors who are hesitant to bring up children’s prognoses (Amidi-Nouri, 2008) may delay families’ communication processes (Mack et al., 2006).

Such descriptions of primary caregivers’ regrets and reflections on their experiences lead us to desire further insight from primary caregivers themselves who speak or avoid speaking with children about the end of life. In order to understand the communication between caregivers and child patients and siblings in the modern New Zealand context, this study targeted all primary caregivers of PPC patients (mothers, fathers, grandparents and close relatives). The scope of this research was broadened to include parents and others who consider themselves primary caregivers of palliative care patients, including other members of the children’s whanau (kin/extended family) (Health Research Council of New Zealand, 2008). The purpose of the study was to unearth some of the reasons that motivate caregivers to speak or avoid speaking with their children about their children’s diseases and impending death and to identify challenges, resources and values they experience.
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5.3. Study Two: Family/Whanau Interviews Method/Theory

5.3.1. Study Two Materials

The interview entitled “Task One: Exploring the Voices of Parents and Whanau, Increasing our understanding of families’ experiences by listening to families involved in paediatric palliative care” (Appendix 21) was conducted with consenting participants.

The interviews were designed with the help of the PPC team and the advice of supervisors and advisors from university, counselling and medical faculties and settings. They led parents gently into the topic of discussing/concealing the impending death of the child with the PPC patient and his or her siblings. Insights into the perceptions of death that caregivers believed their children held and how they communicated was sought as well as advice on approaching families for future research.

5.3.2. Study Two Procedure

Sensitivity to participant safety and comfort took priority over all other aspects addressed by this research. End-of-life decision-making studies have the highest rates of refusal of paediatric oncology studies involving parents (Gattuso, Hinds, Tong, & Srivastava, 2006), though reasons behind that have not been explored. It is worth noting that one person’s health condition may affect all other family members and relationships (Murray et al., 2007). Family systems influence each member’s development and established family rules of communication may affect how the families organise to deal with the health issue. The lens through which families of PPC patients are viewed by HCPs and academics must be sensitive to this issue. Caregivers were assumed to be the heads of families, so were the first people contacted from potential participant families.
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The PPC team members, Heart Children family support people and ‘True Colours’ counsellors spoke directly about the research with families who met the criteria for participation and delivered or posted information (brochures outlining the intent and aims of the study in Appendix 1) to them between February 2010 and February 2011. The CCF’s ‘Caring’ magazine also promoted the research through a promotional note (Appendix 2), to which two families responded. The majority of the families were recruited through the PPC team, who identified them as English-speaking and within an appropriate age range and cognitive ability.

Maori and Asian consultation was sought as a part of the preparation process.
Consultation with a Maori research companion throughout the process to ensured respect for Maori Kawa (protocols) (Jacob, 2011) and the avoidance of breaching rules around anything Tapu (sacred/ prohibited/ restricted). The aims of the research were made transparent in the information sheet to ensure cultural sensitivity and to respect ethical guidelines. Those targeted included caregivers who had children receiving PPC and those who lost a child to a chronic illness. They were notified of the study approximately six months or more after the death of their child as suggested by a study of bereaved parents following the death of their child. Most parents in a study of bereaved parents felt that timing being approached at least six months into bereavement was appropriate (Hynson, Aroni, Bauld, & Sawyer, 2006).

Ethical approval of the study was granted by the Northern X Regional Ethics Committee reference number 4529.

After the 11 families who the PPC team referred were visited by the researcher (myself) to hear about the research and ask questions about their involvement, they received follow-up phone calls to check if they were still willing to participate. After the calls, nine of them chose to take part in addition to two others from other organisations. The two PPC team-
referred families that declined to participate decided that the timing was not appropriate. Next, the primary caregivers were revisited in their homes or at the hospital or other preferred setting to explain the rationale and the procedural elements of the study. Participants read information sheets (Appendix 22) explaining the study and signed consent forms (Appendix 23). Consenting participants completed the interviews in approximately 30 to 180 minutes.

The Principal Investigator transcribed each of the 19 interviews to maximise comprehension and awareness of participants’ statements. They were then analysed as a complete collection, discounting differences between the bereaved and non-bereaved as well as male and female data sets and applying Braun and Clarke’s method of inductive thematic analysis (Braun & Clarke, 2006). The transcripts were stored in NVivo, a computer program for qualitative analysis (QSR, 2011). After transcription, all the interviews were read multiple times and initial ideas for repeating subjects were recorded.

Quotations that related to communicating about the patients’ deaths or avoiding communication about it were coded on a semantic level without interpreting the caregivers’ statements. A few of the same quotations were allocated different codes (e.g. “Talking about death” or “Avoiding talking about death”). Other similar codes that arose from the data were gathered into potential themes (code families). The themes were reviewed by checking the associations to the quotations and the entire data set, defined and labelled.

In the second coding stage, the text spoken by each individual participant within each of the two coded sets was reduced. This resulted in each primary caregiver having a number of condensed statements, which related to communication. All the condensed statements were then analysed thematically. The data were constantly scanned for issues related to the question, “Why did [caregiver] speak/avoid speaking with [child] about their impending death?” Repeating answers were grouped together. The coding procedure was intended to
identify the subthemes specific to each data set and frequencies were noted. In the final stage, I returned to NVivo to check that caregivers’ direct quotations still fitted the themes, drawing from the transcripts to illustrate findings.

A second analysis was run to explore issues beyond caregivers’ communication about the patients’ deaths. Though the interview questions seek to answer questions related to death communication, many parents spoke about other topics during the interviews. Those topics which arose spontaneously from caregiver quotations are the basis of the second analysis.

Quotations that related to themes identified by the author were coded on a semantic level without interpretation. A few of the same quotations were allocated different codes. For example, the following quote was coded as both “Family support” and “Religion:”

I just reassured him that they would be family and people that …that he wouldn’t be scared or anything and he said to me … “I don’t want you to worry about me, Mum,” he said, “I’m going to be okay. I know where I’m going,” because we believe in life after death. And he said that he would… be going back to live with his father in heaven.

(MARIA)

Other similar codes that arose from the data were gathered into potential themes (code families). The themes were reviewed by checking the associations to the quotations and the entire data set, defined and labelled.

In the second coding stage, the text spoken by each individual participant within each of the two coded sets was reduced. Every effort was made to avoid losing the fundamental meaning identified by the researcher. This resulted in each primary caregiver having a number of condensed statements.
All the condensed statements were then analysed thematically. The researcher repeatedly asked, ‘What was the caregiver’s experience and resulting opinion of their situation?’ and attempted to find the answers. Repeating answers were grouped together. The coding procedure was intended to identify the subthemes specific to each data set and frequencies were noted.

In the final stage, the researcher returned to NVivo to check that caregivers’ direct quotations still fit the themes, drawing from the transcripts to illustrate the findings. A Maori research companion inter-coded and revised to verify cultural and methodological appropriateness.

5.3.3. Study Two Participants

Nineteen primary caregivers were interviewed about their experiences in PPC. The participants included five fathers (two of living patients and three bereaved), 12 mothers (seven of living patients and five bereaved), one grandmother (of a living patient) and one aunt (bereaved) from 11 families. Each participant was given a pseudonym.

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Table 2: Study Two Primary Caregiver Demographics (bereavement status and child’s illness)
The children’s illnesses included cancer (10), heart conditions (5), muscular dystrophy (3), and another illness (1). The participants identified as NZ European (9), Maori (6), Other European (3), and Pacific Islander (1).

The age of the PPC patients of participating caregivers ranged from three to 18 years old (at the time of the interview or the time of children’s deaths). The mean age of the child patients of participants was 14.33 years with a Standard Deviation of 1.37 years. Caregivers were also asked about conversations with their other children, who ranged in developmental stage from barely verbal to 33 years old.

5.4. Study Two Results

Most primary caregivers were able to give reasons for their decision, whether it was to speak to or avoid speaking to the child about death. In most cases, caregivers mentioned reasons for both speaking and avoiding conversation. Most caregivers spoke with all or some of their children about death at some stage during their time receiving PPC but gave reasons for delaying communication as well as initiating it. Those who avoided speaking with children about death indicated reasons relating to protecting their children while those who spoke about death did so in reference to preparing them. Their statements are categorized according to three distinct themes within each category (Appendix 24-25) which were labelled and exemplified with quotations. A variety of other topics were explored following the analysis of talking about death.
Reasons for avoiding talking about death described by primary caregivers

Nearly every primary caregiver avoided talking about mortality with their child patients and their siblings to protect them. This avoidance usually occurred in the early stages of the child’s illness:

I needed to protect them from it. Towards the end, the last week, I did say to [sibling], “[Patient] is really not ... doing very well ... I don’t know how it’s going to go.” With [patient], I didn’t ... acknowledge it towards the end ... We needed to protect him. (RUTH)

Caregivers gave various reasons for not talking about death with children.

1. Avoiding negative changes in relationships

Sometimes, caregivers avoided communicating about prognosis to protect relationships, as per others’ recommendations, because children did not want to discuss death or the conversation was not needed, or to avoid being the bearer of bad news or telling the children in the wrong way. Avoiding conversations which might provoke negative changes in relationships which hinged on the advice of others was mentioned by several of the interviewed caregivers:

When I knew that [patient] was going to die ... I spoke with my family and I emailed my brother and sister and mum ... Then she got hold of all of them and they decided as a family that we should protect [patient] from ... you know ... Although we were advised not to, but the family thought that we should protect him from it because he didn’t need to know and why distress him? They felt that under no circumstance should [patient] be told that he’s dying. (RUTH)
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When caregivers perceived that their children did not wish to speak about death, the caregivers did not generally push conversation. Most caregivers mentioned the child’s reluctance to speak about death as a reason for not raising the topic.

About half of the caregivers felt that the conversation was not necessary because the child already understood all the necessary information.

It’s what he wanted. I mean, we... He couldn’t control his [illness]. We couldn’t control it. But he could control what he talked about, so that was absolutely fine. No regrets at all. (FISKE)

He’s never said, “Mummy, why doesn’t my [affected organ] work properly?” And I think because this is normal for [patient], because he was born with this, he’s known this every day of his life, in and out of hospital; he’s had numerous surgeries, it is who he is and because he is [patient’s name] ... he knows no different.” (MARIA)

Seven caregivers spoke of avoiding directly raising the topic of their child’s impending mortality because they did not want to tell them in the wrong way or to be seen as the bearers of bad news.

RATA: “[Luis] and I sat down and decided, ’cause we both work with people all the time, we don’t want to be the bearers of the bad news. We would rather be the supporters.”

LUIS: “The supporters. There, you know.”

RATA: “The carers.”

LUIS: “Because in a child’s mind, quite often he will think, ‘You’re the one that brought me the bad news.’”
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Caregivers avoided talking about prognoses to protect their relationships and those between patients, siblings and others.

2. Avoiding negative changes in emotions

All of the interviewed caregivers who spoke of avoiding conversing about death wanted to protect their families from changing emotions. The caregivers’ reasons are broken into groups focusing on preventing negative emotional reactions, losing hope and blame or regret.

The largest specific reason for not speaking about death mentioned by the interviewed caregivers was to protect children from experiencing negative emotional reactions. A large majority of the caregivers interviewed spoke of this reason.

I’m sort of finding this the hardest, having to see as [patient] gets older and lives longer, he gets hurt more. As his mum, you want to protect them from being hurt as much as possible and you can’t ... I’m finding it harder now than ever because ... I can’t control, you know, his feelings anymore. (KAREN)

Controlling an invader such as a severe childhood illness which would qualify one for PPC is impossible. When caregivers are deprived of their abilities to nurture their children physically, they may feel responsible for providing them with emotional protection.

...They didn’t really know what was going on. We didn’t keep them informed about what was happening. We didn’t want to distress them. You know? (ANGELA)

Caregivers avoided mentioning the possibility of the child’s death to the patient or sibling to keep them from losing hope. They referred to short-term goals or targets to coach children through difficult medical situations.
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I try to reassure [sibling] that everything will go back to normal, eventually. Just, we’ve got to get through this ... surgery, and ... it’s going to take us a little while, but ... we are going to go back to normal. (LANA)

Another problem caregivers mentioned for not talking was wanting to protect others from blame. A small number of participants mentioned that they did talk about the disease because they did not want to bring out feelings of guilt or blame in their children or others.

I didn’t want family members ... to think, ‘Did they give it to him?’ I didn’t want people to look at [father] and think, ‘He gave it to him.’ I didn’t want to be having to explain that I don’t have [disease transmission mechanism]. (TINA)

Caregivers expressed concern over their children’s emotional states. Many avoided disclosing sensitive information from them to keep them stable.

3. *Avoiding negative changes in perceptions*

Protecting children from the unknown, from stigma about death and from losing their innocence were other reasons discussed by most caregivers who avoided speaking about death. Caregivers who wanted to protect their children from the unknown were generally not familiar with how to explain the outcome of their child’s disease.

We got information from [organisation] about things that go wrong about the condition. I find a lot of the information stops when they get to the final stage... [Patient] is kind of in the “Final Stage,” according to my DVD. But there’s nothing after that. And that’s what’s missing... most things you read don’t have that chapter. ...even biographies ...that have been written by people in our situation. They’re either very religious, um, so ... I guess there’s fewer questions. I don’t know, or different
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sorts of questions. I’m not particularly religious, so those books don’t help... There is a gap and I think that relates to our society not being very open about death.

(KAREN)

Some also mentioned that some children may not understand because of age or cognitive abilities. About one-third of the caregivers mentioned this reason as one that might deter a conversation about death.

I certainly wouldn’t have said to a three or four-year-old, you know, ‘Your brother’s going to die one day.’ I mean, there’s no need for that information to be there. But I mean, certainly, whatever age is deemed appropriate to talk about it. I mean, it’s a process, isn’t it? I mean, little pieces of information slowly build up and I guess kids by 10-11-12 are starting to think about a bigger picture and looking up stuff anyway.

... [The information the caregiver collected about her child’s disease] doesn’t tell you [about the final stages of the illness]. Yeah, I guess I could Google... I have, well, I have looked up what-what it’s like to have [resulting disease] and die from [resulting disease], but, um, yeah... So sometimes, yeah, you haven’t got a reference point to go to, so yeah, there’s no real reference points, eh. The moment we kind of ... You know what’s going to happen... We were told 18 months ago he had months left [laugh/sighs]. We’re past months. We’re into kind of... a couple of years now and it’s... You kind of, yeah, we’re sort of in limbo at the moment. (KAREN)

Many of the caregivers wanted to protect their children from being stigmatized by others and to prevent unnecessary lifestyle changes.
It was just easier not to [talk about dying], you know, to everyone do the going around him. Friends, uh, you know. You know, because I didn’t want to change them, walking around, looking like a funeral or ... [laughs] (CASEY)

Many mentioned wanting to protect children’s innocence as well.

You don’t want your kids to have that fear. You don’t want your kids to lose their innocence ... You don’t want them to worry about nothing when they’re little. (TINA)

Caregivers avoided talking about death with children to avoid negative changes in relationships, emotions and/or perceptions.

*Reasons for talking about death described by primary caregivers*

Despite acknowledging reasons for avoiding the topic, most primary caregivers spoke with children to prepare them for death.

We couldn’t have just told them ... and then left it. We’ve had to carry on with the journey and walk with them every day and teach them every day and read the bible every day ... It’s about life. It’s about living. (JANINE)

They spoke for several reasons (Appendix 25).

1. *Acknowledging*

Many caregivers talked about having the sense that patients and siblings knew that the child was dying already. They wanted to be sure they were not lying to or tricking their children by hiding the truth and/or made it a policy to always communicate openly and honestly with their children. Some hoped that through acknowledging the situation, their
children would gain an understanding of the causes underlying their symptoms, thus allowing them to reach their own sense of resolution.

Many caregivers were aware that patients and siblings knew the reality of the situation. Some knew that their children had access to information that they could draw from to infer their prognoses. They wanted to give them closure or avoid the guilt of lying to or tricking them by hiding the truth.

Books... were given to [patient] as well... All the information. We sat down, like every time she wanted to ask questions about it. I think it was just in the first five months, she wanted to know everything. ...We never lied in terms of telling her... to answer her questions... She’d know we were lying and she’d just go nuts....She’s always the one that wanted to know everything: Everything that was going on in her world, she wanted to know about. (CLAIRE)

Most families made it a policy always to communicate openly and honestly with their children. Many also simply spoke about death without denying the child’s death or forcing the information on them.

I’ve always treated my children like... I talk to them like they’re my age, and I just be open and honest with them and I expect the same back... He did say to me, “Be honest about my [disease]. What’s happening?” He goes, “Have you researched it? You know, let me know what you’ve researched.” So I had to tell him, “I have...You’ve been given five years.” You know. He didn’t like that when I first told him, but then he started to go back into the same way of thinking, of, “I can get rid of this, so, Mum,
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I don’t believe you about your five years.” ...I just think, as long as I’m open and honest with him, we ...will get through this and he’ll be okay, you know? (LANA)

Many also simply spoke about death in without denying the child’s death or forcing the information on them. The more information children were given, the more able they were to understand the causes of their symptoms.

It was confirmation, because ... it was hard for her to run. I remember [patient] having that sense of confirmation. She knew that something was going on before with her body ... yeah, she understood it all. (JANINE)

Caregivers who spoke about death or prognosis with their children acknowledged their positions of experts on their roles as PPC patients, breaking the mutual pretence often previously held.

2. Enabling

Caregivers who enabled their children to prepare for death facilitated their children’s strengths. Some spoke with them to allow them to work through their issue and gain peace of mind before the dying process happened. Several wanted to allow PPC patients and their siblings to shift from hoping for a cure to hoping for an enhanced quality of life. By telling their children their prognoses, they were able to open the floor for children to express their wishes.

We just told him. And then [PPC Patient] broke down and cried. And we all cried. And then [Patient], in the doctor’s office, said, “I’m so sorry, Mum and Dad, that I’m not going to make it. And I’m so sorry for [sibling] that she’s going to be an only child.” So he processed it really quickly and apologised, and... When he was
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diagnosed, um, he loved shoes. And, you know, he likes his brand shoes... And when he was diagnosed, he asked if he could have a pair of shoes. So, we called his... diagnosis shoes. And ...after he got the news of his poor prognosis, he wanted to know if he could have prognosis shoes. So that’s very nice... It just made me realise that children accept things and move on a lot easier than what [we as caregivers] did.

(RUTH)

Several caregivers hoped that allowing their children to be upset and release their emotions would enable them to find solutions for their coping.

I told her ...and she was ... just devastated,... absolutely grief-stricken but she is a very practical, pragmatic person... She’s always strong, loving, and she has a good cry, and then she says, “Right. How are we going to deal with this?” Yes, I’ve been very lucky and I just told her the truth. (CLAIRE)

Many confirmed a belief in the positive effect of expressing hope, willpower and strength which enable children to accept the comfort from their families and speak, share and learn how to cope with dying.

She understood ... that she was going to die. We just didn’t know when. Take every day as it comes ... Aw, she was a fighter; she did have her downs. And then she would just really have her ups. [laughter] (CLAIRE)

Caregivers hoped that having their children on the same page (through telling them their terminal illnesses) would enable them to make more informed decisions. Armed with knowledge about their prognoses, children were enabled to make decisions around how to react to the situation around their families, including the patients themselves.
3. Teaching

Most caregivers believed that preparing children for their own and other children’s questions before the death was the best way to ensure that they would not feel overwhelmed with information all at once. These primary caregivers saw talking about the child’s prognosis as a platform from which to teach their children.

Caregivers wanted to reassure their children that they would be there for them, teaching them to seek resources when they needed them. They did not want them to feel afraid.

The first thing that we’ve done is that we’ve been open with them, and ... we’ve become... comfortable with the fact... of her condition because before ... we weren’t comfortable with...saying that she... might not survive, that sort of things were to cause too much fear. But because we’ve learnt to be open about these facts... we’ve got the facts about [disease] and then we’ve got our faith. (JANINE)

By discussing the young person’s illness, caregivers learned how to help their children cope. On several occasions, the PPCT or other HCPs helped them address concerns they did not anticipate. Caregivers talked to children to answer questions and dispel potentially harmful myths.

We actually asked [HCP], “What should we say to his friends? What do you say to adolescents? What will they understand?” And she said, “Make sure they know it’s not infectious?” What? Of course it’s not infectious! But, sure enough, when we actually said that to a couple of his friends and families, the kids went, “Oh, oh wow!”... [laughs] And isn’t that important? That you can’t make any assumptions
what they will or will not know... That was a lesson even to us... We thought they would know that and they didn’t. (CASEY)

Besides talking about death to teach their children about illnesses and open communication, caregivers talked about death to assure children that it was okay to ask for help. Caregivers sometimes spoke about hoping that their children would generalise talking about death with their children to getting help from them in other situations.

I just discuss the medical stuff when it comes up and...Sometimes other things in life bring it out. Like when she’s really upset, ...we’ll talk about that ... All the things in life always bring it out at some stage and then we just talk about it and... just reassure each other that we’re there for each other... I always tell her how strong she is and how amazing she is.

It just makes them have an appreciation. When they’re my age; when they’re old, they’re never, ever going to forget their brother and the love that they had for him. And they’re always going to have an appreciation for people that aren’t so fortunate. I let them be involved in everything ’cause I think it makes them better kids, better people. (TINA)

Caregivers coached their children through their illnesses by talking to them. They expressed hope that speaking with their children about death would teach them to cope with difficult experiences, understand the causes of their difficult situations, answer their questions and appreciate the less fortunate. Lessons to the learned were clearer when caregivers included their children in being educated about their diseases.
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Most caregivers wanted to prepare their children by talking about the child’s mortality through acknowledging the reality of the condition, teaching them to cope with it, and enabling them to navigate through their situations.

**Primary caregivers’ experiences beyond talking about death**

In the second analysis run, primary caregivers spoke about family support, regrets/feelings of blame, disability discrimination, parental roles, internet research, helpful organizations and advice to the interviewer about research. Their statements are described within each theme. Quotes from interview transcripts further exemplify the results.

1. **Family/ Whanau Support**

The most commonly arising theme spoken about by caregivers of PPC patients was the support of their families/whanau. To distinguish between the primary caregivers (usually adults who live in the same residence as the children they care for most of the time) and their extended family/whanau (family members and close friends who may or may not live in the same residence), the term ‘whanau’ will be used for the latter group. However, the true meaning of whanau has been interpreted by some as referring to a more complex ‘group of kin who act and interact with each other for common purposes’ (Metge, 2001). The term ‘caregivers’ will be used to refer to those interviewed and their partners. Most of the interactions with whanau that caregivers spoke about were positive. Families discussed decisions, offered relief or respite support, distracted the caregivers from care giving, avoided involvement in matters related to PPC, supported caregivers emotionally and influenced caregivers’ spirituality.

In discussing decisions with the family involved in PPC, whanau provided
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information to caregivers about their past experiences with death. Many whanau played major roles in the caregivers’ lives. Sharing everything within whanau was common, making decision-making a communal process. Whanau advised caregivers both to hide information in order to protect their children and to tell them to prepare them for death. They filled other needs in PPC patients’ and their caregivers’ lives such as adopting openness to talking about death-related issues or providing a practical service that the family needed.

[Whanau member] was fantastic. He was with us for the last couple of days of [patient]’s life. He just helped with the round-the-clock looking after him. [He] had asked [patient] if he was scared of dying. And [patient] said, “No” when he was sort of semi-conscious. So... somebody mentioned it to him. (CASEY)

Caregivers expressed gratitude for the help they received from their whanau. Their involvement in the care of the patient was almost always referred to in positive terms.

[Patient] has spoken to my mum about it and said what sort of coffin she wants and what colour she wants and where she wants to be buried. She’s already got a place to be buried. My mum took me up there once so I could see where it was and ... I would really like to before the day actually happens... to sit down and talk to her about it (SONIA)

Whanau provided relief and respite support in the form of hospital visits, passing on information, watching caregivers’ children so that they could sleep, and helping with medicine and practical tasks. Siblings were sometimes involved in caring for their brothers and sisters as well. Simply having family present was what most families wanted. One family reported the positive experience of having their family and community around them when a child was very sick:
My mum was already there. [My partners’] mum was already there. We rung our pastor at the church and then from there, everyone else just contacted everyone else. We pretty much had everyone up at the hospital for [patient]. (JANINE)

Whanau provided distraction from the often taxing tasks of caring for PPC patients as well. Increased bonding as a result of the PPC situation was mentioned by several caregivers. Whanau acknowledging the patients’ presence was important to many caregivers as well. One caregiver of a toddler expressed the joy and pride she felt from watching her family members care for each other:

How’d my kids keep me strong? Kept me busy [laughter]. No, not so much kept me busy, but keep me strong... because they made me smile the way they were with [PPC patient]... when he was sick or when he was told he wasn’t going to live for the next five days... They’d make me smile ’cause I was very proud of the kids... and because [PPC patient] loved the kids... Yeah, when I could sit back and just watch them for an hour and not even be involved... that would give me so much pleasure; so much joy; you know? I didn’t have to be cuddling [PPC patient] to get that... feeling. Just watching him with the other kids would give me that because he had so much... he just loved the kids [cries]. (TINA)

Some whanau, however, avoided involvement with caregivers and their children after learning of their illness. This was usually seen by the caregivers as a negative reaction to the prognosis. Whanau was perceived as not being able to handle the situation, being overly hopeful, allowing the family privacy (especially at the time of death). However, a couple of caregivers mentioned feeling burdened by the family with too many questions about the PPC patient’s illness.
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A lot of people, family members and things, they know what he has but they don’t want to talk about it. They will change the subject. They will not talk about it. It’s amazing how few people actually even know it’s staring them in the face will talk about it. (KAREN)

Whanau supported caregivers and their children emotionally as well. Siblings of PPC patients were consistent ‘rocks’ (TINA) for them and normalised the situation by actively participating in caring for the patient. The affected family’s whanau cried with them and just asked how the caregivers and their children were doing to support them. Many caregivers acknowledged the roles of whanau as outlets for the siblings of PPC patients when they may not want to discuss things with primary caregivers.

After I’d spoken with [PPC patient] and the team at the hospital about the decision that was made, then I, obviously with my family, I talked with [sibling] so that she feels that she has support; she can go to not just me. She can talk to her family and they’re there to support her. (MARIA)

I mean, it’s our whole family’s thing and I guess... we talk about it amongst ourselves. (KAREN)

A few caregivers addressed spiritual concerns with their children and whanau. They preferred to face death as a family unit and discussed its meaning with whanau, often in the context of religious beliefs.

[PPC patient] was surrounded by us, and ... ‘cause we are of Christian background, and ...we have spoken with them about death, and, going to Heaven, and having eternal life, and that one day, you know, we’d all be together. So, ...we had prepared him in that way.’ (RUTH)
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Social support was sought through family/whānau ties in caring for PPC patients by all the interviewed caregivers.

2. Regrets/Feelings of Blame

Most caregivers expressed experiencing regrets or feelings of blame about things relating to caring for their PPC patients. Some felt guilty about the outcome of the illness, communicating distress about not being able to cure the illness or making decisions that led to the child’s illness. These often stemmed from decisions made in consultation with doctors or waiting longer than caregivers felt they should have to report symptoms. A few blamed themselves for not noticing symptoms that could have led to earlier detection of their children’s disease, such as a decrease in their child’s food intake a few days before diagnosis.

Now I look back, I might have noticed; his intake of milk might’ve got slower, like not as much, probably three days before that. But it was only a real slight, slight, slight ... you know? (TINA)

Most primary caregivers expressed helplessness at their inability to cure their children of their illnesses. One mother spoke of feelings of blaming herself:

You can fix anything practically, but you can’t fix that... You can find a solution for anything in life but not that... That’s when you realise how inadequate... that you really are. (ANGELA)

Most caregivers were concerned about time with their children. Many of them chose to tell their other children about the PPC patient’s illness to prevent anticipated guilt over ‘what ifs’ (TINA) and ‘if onlys’ (FISKE). However, a few caregivers regretted telling their whānau about their child’s illness because the whānau then stopped visiting. Some wished they could spend more time with their children without worrying about them or wishing they
would get better. They wanted to focus on their children’s living rather than their illnesses or impending deaths.

I just wish that I’d just lived and enjoyed [patient] at... in the present instead of trying to hope for something. (ANNETTE)

A minority of caregivers expressed some guilt over wanting their child to die to make her or his pain end. Their hope for ending their children’s pain was complicated by a desire for family life to return to “normal.” One expressed guilt over wanting their child to die to make his pain end:

You feel guilty ’cause when you’ve got a child that’s sick... You’ve got to be there and look after your kids as a parent, but for me, what was most difficult was actually wanting him to die in the end. ’Cause I wanted it all to end. I couldn’t cope with it. It ...was affecting us as a family, it was affecting the kids, it was affecting every year...

It was all-consuming. (ANNETTE)

Caregivers spoke of the burdens associated with caring for their terminally ill children and their siblings alongside a regret or guilt for many of their negative feelings. They generally expressed wanting the situation to improve but frustration over their inability to change it. Regrets and blaming were a part of many primary caregivers’ lives during and after caring for PPC patients.

3. Disability Discrimination

Themes relating to being discriminated against on the basis of disability included others not knowing how to act around the PPC patient, adjusting to a new way of living and communicating with the patient, and normalizing disability.
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Those who did not know how to act around the patient often had little experience with people with disability and would either ignore, stare at, or forget about the differences in ability between the patient and a nondisabled child.

People look at you when you’re different... when you’re in a wheelchair ...or got his tongue stickin’ out or... People might come into the house that couldn’t deal with [PPC patient] being sick... Whether you call that weak or selfish or what, I don’t know... but ...people that gave [PPC patient] time; they would knock on the door and they’d go, “Hello!?” and straight away you’d see [PPC patient] either smiling or he’d start talking to them... A couple of people come into my house and they ...haven’t acknowledged [PPC patient]... Obviously, they’re a bit scared of [PPC patient] ...but after a certain time, ...they could see that, “Aw, he does communicate back!” and they would try to communicate with him. [PPC patient] would ignore them. So he was very clever. (TINA)

The caregivers’ families had to adjust to a different way of living and communicating with the PPC patient. Patients were often very dependent on caregivers and tools such as computer aids, label cards, and non-linguistic noises. They adapted to making quick decisions to maximise enjoyable activities in phases of patients’ illnesses when they felt better. Several children changed their activities to focus on interests that their bodies could accommodate more easily (such as shifting an interest in rugby to an interest in music). Caregivers attempted to fulfil their wishes while maintaining normality.

We had a window period between [treatments]. We had a week. And we planned that trip within a day. I think we booked the tickets on the date and then we were gone ... but then [we] also try to live as normal as we can. ...He still needs to do his chores. They’ve got a paper run, the two kids... and he needs to make his bed. (RATA)
Most caregivers who mentioned discrimination on the basis of disability were comforted by those who attempted to normalize disability. A couple of caregivers spoke of feeling isolated and not fitting into the mainstream pattern. When siblings helped to care for the patient, the condition was hidden, or the patient sought others who had similar experiences, caregivers felt more ‘normal,’ which was generally spoken about in a more positive light.

I don’t know whether families without disabilities feel on an island as well, maybe we all do but... There’s times where you feel really left out. (KAREN)

The same mother spoke of her adolescent son being unhappy because of missed developmental milestones. She was concerned about social isolation resulting from his disability. Dealing with disability-related issues was a large part of many caregivers’ lives. Many caregivers felt isolated and stigmatised due to their child’s illness.

4. Parental Roles

Caregivers of PPC patients held tightly to their parental roles. They cut unnecessary tests and pain-provoking events to maintain their children’s quality of life and protected their children. Several caregivers noted sensing that something was wrong before doctors confirmed the children’s illnesses and mentioned frustrations with doctors who perceived them as paranoid. The caregivers persisted in asking HCPs the same questions and asking for the same medical tests until they were satisfied with answers.

[The doctors said] “Do this test” and, “blah, blah, blah,” and deal with the parents later and explain everything to them... It was just all this information because it’d got to that stage after the biopsy; I just looked at them and I was just so angry... I just kept swearing. (CLAIRE)
Many caregivers expressed a sense of helplessness and a deficiency as a caregiver. They wanted to help but were usually unable to control their children’s unanticipated traumas.

The whole experience for me was devastating,... overwhelming,... I didn’t expect … for him to go into [medical issues]. I was not prepared for that. I thought [patient] had already gone. Then when we got to the hospital, ... He wasn’t breathing on his own, so they had to intubate him and give him a breathing tube. And the whole process, I felt like I was disconnected. (MARIA)

Caregivers wanted to be taken seriously and listened to. They described situations in which all they wanted to do was to follow HCPs’ advice. They generally noticed when something was wrong. A few of the caregivers’ words indicated that they might not feel that they were taken seriously.

He just kept saying, “You know, I’m positive it’s a second bout of [disease]. You need to take her straight up to [hospital], not go home, not go downtown.” And I was like, “I’m not going to go downtown and I’m not going to go home! If you say I need to go, I’m going to go!” ...And [patient] was like, “No, I just want to go home ... There’s nothing wrong with me!” and that was the other tell-tale sign too. She would like go off the deep end, like loose her temper really quick ... And then just stand there and laugh about it, which isn’t normal for her. (CLAIRE)

Primary caregivers mentioned the importance of their roles as parents in the interviews.

5. Internet Research

Caregivers shared positive and negative perceptions around using the internet to research their child’s illness. A few gained hope from reading about others’ triumphant fight
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against the illnesses of their children. Others used texts given to them by organizations to answer their children’s questions and share information with their children’s teachers and family. They often turned to the internet for advice and answers.

I didn’t, as a mother, want to accept it; the fact that he was terminally ill. ...That night, I went onto Google. And I Googled and Googled. And for the next few days, I just Googled and Googled. And I came across a man ... who had the same [illness] as [PPC patient]... and he’s still alive... So I got a bit of hope. (RUTH)

On the negative side, some caregivers felt overwhelmed by the amount of information about the disease which was sometimes inconsistent. Others expressed frustration over the lack of information. Most lost sleep over spending time researching and looking for solutions or spoke about the lack of information about how patients with her adolescent’s illness die. When primary caregivers used the internet as a tool to access information, they obtained mixed results.

6. Helpful Organizations

Caregivers mentioned ways which professionals helped and ways for them to meet their needs more adequately. The organizations mentioned included the teams that recruited them (the PPCT, Child Cancer Foundation, Heart Children and True Colours), psychiatrists, medical teams, health organizations, churches, nurses, school counsellors and 0800 numbers. The organizations supported caregivers by offering practical support (medical information, pain control, groceries, accommodation, etc.), advice about communicating with their children, and emotional comfort:
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I think it’s really important to... establish that people know what’s available and who they can talk to: the Palliative Care Team, their own medical teams, psych liaison, the health organisations; CanTeen, Child Cancer Foundation. There are people there but it is such a difficult issue that people may not be able to ask for help. (CASEY)

The organizations mentioned by caregivers helped them develop philosophies for coping with the illness and communicating with children. They generally suggested respecting patients’ requests for privacy and normalcy and offered tips to help the children cope. They ensured that families were cared for. Most of the organisations mentioned took a family-centred approach.

When [patient] was first diagnosed, [disease-related organisation] did a lot to help and... they were really, really amazing to begin with... Those organisations were really helpful... Having continual check-ups... at Starship was very helpful too, because then someone would say, ... “You’re not coping very well. How about you see these people?” (KAREN)

Organisations that provided emotional support such as the PPCT at Starship (Figure 5) generally asked how the families were doing and often focused on caring for the siblings while their caregivers juggled other tasks. They also acted as counsellors and helped families address frustrations, which often had to do with emotional states and coping mechanisms.

If you struggle to talk... with your child, get some professional help. Get somebody who can give you ideas as to how to help... If you need help from your church or your
community, some communities cope with death particularly well and some don’t. 

...Some communities cope particularly well with disability and some don’t. I think it depends on your culture, your upbringing, uh, but definitely seek professional help from the palliative team that care for you. (JACKIE)

Although the vast majority of caregivers provided very positive references to supportive organisations, some mentioned barriers to receiving the help offered. A couple of caregivers stated that they would not acknowledge the situation and one even left when help from a team was offered. One mentioned seeking out unhelpful organisations because she did not know who to whom to turn.

Often you go to the wrong places for information. You think that Income Support or somebody like that is going to support you because they give ... some money every week. Well, they don’t support you; they do the opposite. (KAREN)

Some did not want their children to be associated with the stigma of PPC but suggested that medical teams should make contact and involve themselves to help families.

I really didn’t want people coming under the banner of “Palliative Care Team,” but the team handled it very well and would come and see him anyway ...because he’d been having back pain and [doctor] would be involved because he was an expert in helping with pain issues and treatment and looking after people at home rather than in hospital, and things like that. And [patient] wasn’t stupid and I think he knew. (CASEY)

The majority of the interviewees mentioned at least one organization that influenced their experiences caring for their PPC patient and their siblings.
7. Advice about Researching PPC

In advising researchers in the field of PPC, primary caregivers often mentioned their motivations to participate and the utility of the research. Many of the interviewed caregivers mentioned personal reasons for participating and wanted to help more than just other families in their situations. They spoke of the value of the research as a part of their own experience.

Almost all of them mentioned that they wanted to help other families by taking part in this study. They hoped that the outcome would benefit families in similar situations and help the participants themselves to get out of a “dark hole” and be proactive in their lives by expressing emotions. Some hoped that the research would back up advice given to them by medical teams. They wanted practical outcomes. One hoped that this research would back up advice given to families from the PPCT. They hoped that it would encourage and comfort others.

I think, when the child is alive, maybe if there is research that shows, you could back up the Palliative Care Team by saying, “There is research that shows that children accept the imminent death quite well. And that it’s okay as a family, for you to ask them how they feel about death. Yes, they will be sad, but they will be able to handle it. (RUTH)

However, most of the caregivers advised against generalisations, mentioning that each family will likely be different in their approach to discussing illness and death in PPC.

I don’t think anybody can say what’s right or wrong for each family. I think you’ve got to judge each family on the situation they’re in... which is very hard. Very hard. (JACKIE)

Most caregivers gave practical advice, such as noting the importance of ensuring
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sensitivity when approaching families, talking to caregivers before children, being open and honest, talking in age and culturally-appropriate ways and listening more than talking. Many spoke of improving their child’s life as a major priority. Some expressed that talking about it was a positive coping mechanism. Research was one route through which the expression was welcomed.

It’s important to express that death is part of life and ... it’s important to have information out there ... so that they can, you know, talk about it. Because it’s healthy to be able to express your emotions and feelings and... it’s a process. (MARIA)

Opening the floor to enable dialogue was critical to facilitating communication between caregivers and children as well as between the members who participated in this research. Though they were informed that this research would not benefit participants directly, most caregivers interviewed expressed gratitude for being able to talk about this topic.

One caregiver felt that a blunt approach was best in approaching families. Be open and candid... just completely open about it because most people aren’t. [laughs]... They’ll probably want to talk about it... The more honest that the conversation is, the more help it’s going to be. So ...even from very, very early on, no pussy-footing around. (KAREN)

Some caregivers mentioned that collecting data from them may be better later in their process of being involved in PPC while others suggested that interviewing when the child is still alive would be of greater benefit. Some also preferred to be interviewed in private while others had children playing, cuddling and doing things in the same room as they answered the interview questions.
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[To daughter:] I’m having some quite deep conversations at the moment. Could you just go and hang for maybe 10 minutes? Thanks, Baby. And if you could just pull that curtain across there. (KAREN)

[To crying son:] Yes, darling, what’s the matter? Sorry, if I can just deal with this now… [rustling as caregiver goes to kitchen and helps two sons.] Alright, we’ll just have a cuddle… Anyway, so… (MARIA)

Thus, a number of interviewed caregivers spoke about speaking with their children about death, avoiding the topic, family support, regrets/feelings of blame, disability discrimination, parental roles, internet research, helpful organizations and advice to the interviewer about research. The significance of these may be considered in a number of ways.

5.5. Study Two Discussion

Caregivers’ comments regarding communication at the end of life indicate competing desires to protect and prepare children. Whether communicating about the child’s impending death is a means by which they might achieve those aims is a question each individual caregiver assesses differently.

Today, health professionals generally believe that many children, including young children, know when they are dying (Stillion & Papadatou, 2002) and may or may not want to talk about it (Dunlop, 2008). One of PPC children’s immediate needs is knowing that caregivers will always be there with them (Silverman, 2000). The present results suggest that if these goals are to be achieved, consideration needs to be given to how the apparently conflicting aims of preparation and protection may be achieved. Similar concerns have in the past been raised regarding communication with adults about diagnoses such as cancer (Knight & Field, 1981) but it is now widely recognised that the provision of information to
Those who want it can be associated with positive psychological outcomes. Most patients prefer confident, knowledgeable HCPs who approach them with realistic, detailed prognostic information and assure them that pain will be controlled (Hagerty et al., 2005). It may therefore be possible to reconcile the conflicting aims by exploring the possibility that possessing information may serve to reduce anxiety and uncertainty without eliminating hope.

Though some caregivers avoided speaking about death with their children to protect their childhood innocence, children may know more about death than they expect. This may be particularly true in New Zealand where caregivers’ slightly underestimated their five to seven-year-old children’s accuracy when answering questions about death as a biological concept (Gaab, 2012) and many members of the indigenous population involved children in death practices/ tangihanga (Jacob, 2011). Communication at the end of life may differ from what parents expect.

Study Two results support the notion that primary caregivers value protecting their children and see hiding information from them as one way of doing this. Such findings are consistent with previous research connecting parents’ reluctance to discuss their children’s impending death to a number of factors (Kane & Primomo, 2001), including a natural tendency in families of children with terminal illnesses to avoid being the bearer of bad news, feelings conflicting with the caregivers’ role as nurturer and protector, and a lack of confidence in their ability to communicate effectively regarding such issues.

In several previous studies, parents of chronically ill adolescents acted in protective manners which conflicted with young people’s desires for independence (Taylor et al., 2008). Parents who were felt by adolescents to be were too controlling were faced with lies from their children about their self-care. In order to meet the needs of caregivers of PPC patients,
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health professionals, friends, family and researchers may help by listening and responding to families on an individual level. Almost all caregivers interviewed in this study mentioned the uniqueness of their situations. However, despite this, several concerns were repeatedly mentioned across participants.

The support of caregivers’ families/whanau generally came from the consistency of their presence for the caregivers and their children. Whanau may be able to provide much needed stability for families receiving PPC by just being present. Some caregivers regretted not being able to cure their child’s illness and not spending as much quality time as they would have liked to with their child. The help of whanau and advice from supportive organisations may help caregivers resolve these issues.

The themes detected by the researcher related to each other on multiple levels. Consistent, responsive family support, which was mentioned by nearly all the participants, in conjunction with the professional support of organisations and medical teams, may help families address the above mentioned concerns. Families and organisations may help caregivers find solutions in order to minimise regrets, normalise the situation and the patient’s disability, and mediate the internet research that caregivers seek.

In some cases, caregivers may need the most support in minimising regrets and dispelling myths which they and others have adopted as truths. In studies of children who lost a parent to a terminal illness, the openness of the surviving caregiver and the sharing of information about the death have been associated with better psychological outcomes in children (Siegel, Raveis, & Karus, 1996). Armed with the knowledge of things that other caregivers have done and said, they may make informed decisions about how to speak with their children about impending death. Things to consider include studies such as those involving important decisions. Caregivers may benefit from being informed of studies such
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as those involving caregivers’ regrets around speaking about death with terminally ill children (Kreicbergs, 2004).

There is currently a gap in the literature around integrating PPC patients’ perceptions of their illnesses regarding disability. Most caregivers mentioned their child’s illness as a disability during at least one point in the interview. Themes arose which related to discrimination on the basis of disability. The majority of caregivers felt that many people did not know how to act around the PPC patient. They mentioned that their children were often ignored or stared at. Some mentioned a desire to have things “like normal” despite their prognoses or disabilities which would not allow them to support the lifestyle they were used to. This is consistent with a study of parenting children with disabilities which found that stressed parents perceived their children as ostracised by their communities, leading to social isolation (Hall et al., 2012).

The theme of “parental roles” overlapped greatly with that of wanting to protect children by avoiding discussions of death. As with all the other topics, the theme was initially provoked by questions about talking with children. Since talking is one of the few activities primary caregivers have control over, it is plausible that words exchanged between caregivers and children carry extra weight when children are at the end of their lives. Many primary caregivers felt powerless in the face of their child’s illness. Like the parents of younger American oncology patients, the caregivers were robbed of their ability to provide daily support to their children, not to mention looking after them in the future (Bluebond-Langner, 1978). Their supportive caring roles were consumed by their child’s illness, HCPs and medical equipment.

The link between parental roles and not telling children their prognoses or those of their siblings may be explained by social exchange theory (Afifi & Olson, 2005). The secret of a
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child’s prognosis, which robs primary caregivers of their control over caring for and protecting their children, was perceived as a highly identity-threatening and personal secret. Many of the primary caregivers guarded the negatively-perceived secret of their children’s impending deaths. It was likely that they did so out of a concern about influencing the way others related to them (their parental roles). Primary caregivers who chose to conceal information from their children acted in adherence with social exchange theory in trying to regulate the amount of information that their children received.

Primary caregivers often used the internet as a research tool. As more healthcare consumers gain access to the internet, more begin using it as a research tool to search for answers in such unfamiliar domains (Bhavnani, 2002). Health information has been obtained via the internet from 60-80% of its users (Fox & Rainie, 2002). Several caregivers in this study spent hours online trying to find solutions to their children’s problems, sometimes resulting in them travelling to seek out alternative treatments. The effect of this research and the resulting actions of caregivers is not known. Perhaps HCPs could instruct caregivers on useful domains in which to begin their searches. They may also help by encouraging conversations around the information obtained to dispel myths found when researching their children’s illnesses.

Most of the findings of this research are consistent with other studies, indicating that there are similarities between families receiving PPC across cultures. Parents of oncology patients in Australia required help from multidisciplinary health professionals, family and friends and sought practical assistance in caring for their ill child and their other children (Monterosso et al., 2009). The sample of caregivers interviewed in Auckland drew resources from similar sources.
Bereaved and non-bereaved caregivers who took part in this study agreed with those of others that the use of in-depth qualitative interviews promoted parent empowerment (Hynson et al., 2006). One may conclude that semi-structured, compassionate interviewing is a preferred method of investigating families’ experiences.

**Limitations**

This study is limited by several factors. In order to maintain high ethical standards, sensitivity to participant needs took precedence over scientific inquiry. The sample interviewed was carefully selected and filtered by HCPs and family members and was certainly not a random sample. Participation by caregivers was voluntary and participants were monitored for signs of discomfort. However, none of the participants asked the interviewer to stop interviewing or withdrew information.

Some caregivers may not wish to participate in death studies research for personal (79%), cultural (21%), religious (21%) and other (26%) reasons (Gaab, 2012). Two caregivers referred by the PPCT chose not to participate but expressed their respect for the ‘need for the research.’ Unfortunately, the nature of this research question and the group from which it drew participants are highly sensitive. Due to the method of data collection (which requires openness to verbal communication), voluntary participants are likely to be from a small, self-selected part of the population. It is plausible that those who did not discuss death with their children did not want to discuss reasons for so doing with a researcher.

All research, especially qualitative research, must be viewed through a critical lens. Findings come from small and not necessarily representative samples so may not be generalized employing the researcher as the main tool. However, qualitative data may also be more likely than quantitative methods to challenge the dominant discourse and illuminates
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participants’ experiences (Thomas, 2011). Though not acknowledged by thematic analysis, the interviewer witnessed several children cuddling caregivers when they cried on occasion during the interviews. This may be a demonstration of children protecting their caregivers and worthy of further investigation through other methods of analysis.

Practice Implications

Caregivers face a number of common challenges and concerns during and after caring for a child receiving PPC, including those around communicating with children at the end of life. They may already have the skills they need to help them make decisions. When deciding whether or not to open discussions about their child’s impending death, caregivers may draw on parenting skills which parallel those developed while making other decisions for their children. An individualized approach may be taken when helping caregivers decide how to communicate with children at the end of life, considering caregivers’ perceptions of their situations and their children to help facilitate effective communication within families receiving paediatric palliative care. Health professionals and people who support families undergoing the process of caring for a child receiving PPC may assist caregivers by addressing the mentioned concerns.

It is also important to assess issues related to families’ coping after children’s deaths. After the death of a child, the risk of psychiatric hospitalization has been shown to increase among bereaved parents, especially mothers (Li, Laursen, Precht, Olsen, & Mortensen, 2005). Consequently, relationships between family members, such as those with siblings, may also change (Foster et al., 2011). As one parent noted, “a lot of the information stops when they get to the final stage... there’s nothing after that.” How communicating about the child’s impending death affects their subsequent coping warrants further exploration.
Chapter 6. STUDY THREE—PERCEPTIONS OF YOUNG PEOPLE RECEIVING PPC AND THEIR SIBLINGS

6.1. Abstract of Study Three

Research is required to illuminate the perspectives of young New Zealanders receiving PPC. Limited studies of their perspectives have been conducted in NZ to date. The goal of this study is to explore the perspectives of young people with life-limiting illnesses and siblings through diary records.

A qualitative study of the diaries and responses of 16 PPC patients and siblings aged 9-22 living in the Auckland area was conducted through written and verbal accounts and interpreted using inductive thematic analysis.

The findings revealed that young people involved in PPC held a number of concerns and held common values. Young people expressed ideas relating to the special treatment of patients, spending time with family, judgment or discrimination, being understood or understanding and mortality. Young people voiced advice, perplexity, gratitude, pride and pity in their accounts.

The quality of their families’ lives is important to some young people involved in PPC. When caring for young people receiving palliative care, factors that healthcare providers may want to consider include the direction of special treatment, time spent by families and young people’s perceptions of prognosis. A non-judgmental, open approach without discrimination is recommended for consulting with patients and siblings in determining their needs.
6.2. Literature Review of Opinions of PPC patients and siblings

As a method of caring for children with life-limiting illnesses, PPC has grown significantly as a medical field over the past decade (Feudtner et al., 2011) but still has yet to catch up with adult palliative care services. In a PubMed search using the keywords “palliative care” returned about 35,000 entries contrasting with about 2,000 returned from the key words “pediatric palliative care” or “palliative care & children” (Knapp, 2009). Both these fields are expanding quickly, however, with about 40,800 returned using the keywords “palliative care” contrasting with about 3,100 returned from the key words “pediatric palliative care” or “palliative care & children” in a similar search conducted in April, 2012. Children and young adults with life-threatening conditions who receive support from PPC teams are diverse in terms of disease, culture, developmental age and support network. Their home and school environments also differ depending on the mentioned factors. Unlike adult-oriented palliative care recipients, most PPC patients remain alive and continue with palliative (often alongside curative) treatment for a year or more after initiating it (Feudtner et al., 2011). The most researched areas of PPC include relieving symptoms, coordinating logistics and care, and supporting psychosocial needs and decision-making (Knapp, 2009). Overall, however, the voices of children receiving PPC are often absent from conversations.

Consultations about young people’s healthcare do not usually include patients due to fears, uncertainties and differing opinions of healthcare professionals and families (Coyne, 2008). Though most young people want a say in things that affect them (Powell & Smith, 2009), researchers of PPC often collect data by questioning medical personnel, even in conducting studies of children’s spirituality (Davies et al., 2002; McPherson & Thorne, 2000). This may be problematic if those interviewed cared for the children only for a brief
Issues of consent are some of the biggest barriers to accessing young people’s opinions (Alderson & Morrow, 2004; Bluebond-Langner & Korbin, 2007; Christensen, 2004b; Coyne et al., 2009; Gattuso et al., 2006; Hadley et al., 2008; McPherson & Thorne, 2000; Powell & Smith, 2009; Thomson, 2007; Tomlinson et al., 2007). The effects of agency and power are not clearly defined in childhood research, although there are exceptions. Some HCPs and researchers still advocate hearing children’s voices through their behaviours, artwork, and words as interpreted by paediatric nurses (McPherson & Thorne, 2000). The direct words of children receiving PPC are very quiet in the existing literature.

One literature review of the experience of adolescents with chronic illnesses revealed themes including maintaining friendships, normalising life, the importance of family, views of treatment, school, relationships with HCPs and the future (Taylor et al., 2008). Many adolescent patients see themselves as the same people with and without their illness (Woodgate, 2005). They want to be treated as such by others; responded to as if they are not ill but able to receive special treatment at times when it is needed. They advise others in their situations to change their attitudes to accommodate the illness by communicating with others to facilitate understanding (Taylor et al., 2008). Adolescents and children may value the ability to talk to the people around them about concerns. In one study, adolescents ranked the value of speaking freely about their fears and feelings only second to pain management on a list of EoL psychosocial needs (Jones, 2006). A culture of openness, free of taboos and restrictive rules around conversation topics may allow young people to express what bothers them.

Societies are dictated by rules governing how we live as well as how we die. Laws and
unspoken social codes have a bearing on the things we do, speak about and are exposed to.

When young people receive negative reactions from adults to whom they mention death, they begin to understand death’s taboo nature in Western culture. Paediatric oncology patients in the US have been reported to maintain a sense of mutual pretence with caregivers: both parties know that the other is aware when a child’s death is near, but both chose not to talk about it in order to protect the other and their roles as adults and children (Bluebond-Langner, 1978). It is clear that some primary caregivers in NZ do not talk with their children directly about death (Gaab, 2012), but do children avoid the topic with their caregivers as well? The roles of caregivers and children are similar in NZ to those in the US but may not be the same.

Care received by families is frequently fragmented between hospital units and institutions (Amidi-Nouri, 2008), further complicating matters around communication. Families must often seek treatment from multiple HCPs. Consistency is rare, thereby making relationships and trust more challenging to maintain. Hospitals are far from ideal places for difficult conversations. Additionally, medical facilities are often hierarchical environments with isolated social workers in which emotional standards of care have not been established (Browning et al., 2007). Most doctors enter the field to save lives, not to help children die comfortably, yet they are usually the first ones consulted to determine PPC patients’ needs. Studies of the perspective of the families involved are not abundant in the literature (Amidi-Nouri, 2008).

Children are the experts of their own lives, despite their obviously vulnerable positions. Young people may appreciate the opportunity to take part in research. They, like their caregivers (Gaab, 2011), may be grateful for the opportunity to pass on advice to other families and HCPs. Children often enjoy talking about the supportive people in their lives. As
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one caregiver recalled, “One of the things that really helped [a five-year-old patient] and that made him smile, even toward the end, was talking about all the support he had from different people that were in his life. He would name all these people” (Bearison, 2006, p. 155).

Putting children in the role of expert consultant may actually empower them rather than make them vulnerable.

There may be a need to inform young people of certain information following the delivery of their prognosis to them. For example, one physician reported from experience, “When you diagnose a kid with cancer there is always something you say to the family, and then you have to have the Kleenex box right there because, for example: you say, ‘There is nothing that you did. It wasn’t that you went out in the rain without your shoes on. It wasn’t the cold that you had...There was nothing that you did to cause this to happen.’ You say that, and you don’t realize what a powerful thing you’re getting into until you do it once or twice and the family gets hysterical. So you come to learn that that’s what they are carrying as their baggage, from the first moment” (Bearison, 2006, p. 169). Particularly needed is an understanding of how critically ill adolescents view themselves as they progress through their disease trajectories (Woodgate, 2005). Through capturing families’ and children’s experiences, we may be better able to understand ways to relieve their suffering and improve the delivery of care to them.

In order to understand the concerns, cares and interests of PPC patients and siblings, the present study consults children themselves. The study aims to identify factors that affect young people coping with disease and impending death in NZ.
6.3. Study Three: Young People’s Perspectives Method

6.3.1. Study Three Materials

Recent research suggests that palliative care patients are interested in and may benefit from participating in research (White & Hardy, 2010), especially through verbal communication. The instructions entitled “Study Three: The Voices of PPC Patients and Siblings” (Appendix 26) were given to consenting caregivers. Those who consented to allowing their children to take part were given information sheets for their children (Appendix 27). Following the signing of consent forms (Appendix 28), further instructions (Appendix 29) were written on the inside covers of blank diaries (Figure 6) or given verbally. Participants chose whether they wanted audio recorders or locked diaries in which to record their daily perceptions. Most chose to write in diaries, but a few opted for audio recorders to compensate for motor control problems. Some of the children, such as those with muscular dystrophy, found it easier to speak into the recorder than to press their pen on paper. Participants who chose diaries were also given sheets of stickers which contained bears displaying various emotions. The method was designed with the help of advisors at the University of Auckland and the PPC Team. Study aims were child-focused; participants were encouraged to express feelings about the changes in their lives but no attempt was made to persuade them to feel other than the way they did. Not only was this lack of persuasion important for the validity of the research, but for children’s mental safety...
through the changes in their lives (Tomoana, 2010). The “Bears” (Skylight, 2011) emotion stickers were not labelled with any words, so children were not constrained by emotions already described for them.

6.3.2. Study Three Procedure

The research aims were made transparent in the information sheets (Appendices 8-9) to ensure cultural sensitivity and to respect ethical guidelines. The participants were recruited through the PPC Team, Child Cancer Foundation, and Heart Children Foundation (now called @Heart) in Auckland and True Colours in Hamilton, New Zealand between February 2010 and August 2011. Young people receiving PPC were contacted only after verbal consent was obtained from their caregivers.

The PPC Team members, Heart Children Foundation (@Heart) family support people and True Colours counsellors spoke directly about the research with the families and delivered or mailed information to them. The Child Cancer Foundation’s “Sharing” magazine (Appendix 2) also promoted the research. The majority of the families were recruited through the PPC team, who identified them as English-speaking and within the age range and cognitive ability to be able to verbalise or write their perspectives. Only participants whom the named organisations were willing to contact were recruited.

After receiving the permission of the young people’s PPC providers and family, the principal investigator (PI) met with the young people and spoke about the study. Willing participants received participant information sheets and their preferred recording medium (blank 100-page journal or audio recorder). Caregivers were informed that the recordings were for the children’s use only.
At the end of each week, participants were visited by the PI (myself) and given a form which asked, (1) “Would you like another [journal or recorder]?” (2) “Did you find it useful or helpful in any way?” and, if yes, (3) “How was it useful?” (Appendix 30). The form also asked the participants what they would like to be done with their data after the study was completed. After data were collected, the recordings were only viewed by the PI and her supervisors.

*Analysis*

The PI transcribed each of the diaries and recordings. They were then analysed all in the same set, as a complete collection, discounting differences between the patients and siblings as well as male and female data sets. The method of qualitative examination followed the rules described by Braun and Clarke’s (2006) inductive thematic analysis. The transcripts were stored in NVivo, a software program for qualitative analysis (NVivo qualitative data analysis software, 2010). After transcription, all the interviews were read multiple times and initial ideas for repeating themes were written down. All quotations that related to PPC were coded on a semantic level without interpreting the young people’s statements. A few of the same quotations were allocated different codes (e.g. “special treatment of patients” and “spending time with family”). Other similar codes that arose from the data were gathered into potential themes (code families). The themes were defined and labelled, then reviewed by checking their associations to the quotations.

All the condensed statements were then analysed thematically. Repeating codes were grouped together. The coding procedure was intended to identify the subthemes specific to each data set and frequencies were noted.
In the final stage, the PI used NVivo to check that the young people’s direct quotations matched the themes, drawing from the transcripts to illustrate the findings. Each participant was given a pseudonym to protect participants’ identities. A Maori research companion inter-coded, revised and compared her results to those of the PI to verify cultural and methodological appropriateness. Two confederates (other postgraduate students) at the university inter-coded to insure accurate interpretation of the quotes as well.

6.3.3. Study Three Participants

Sixteen young people aged 9-22 years participated in this ethnographic study. The participants included seven PPC patients, three brothers and six sisters from eight families. Patients’ illnesses included cancer, heart conditions, and dystrophies.

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Table 3: Study Three Young People Demographics (Sibling/Patient status and patient’s illness)

6.4. Study Three Results

Young people indicated that the special treatment of patients, time with family, judgment or discrimination, being understood/ understanding and mortality were of concern in their daily recordings.
1. Special treatment of patients

The special treatment of PPC patients mentioned by participants generally involved an unequal allotment of attention given to patients. The attention was given in the form of practical and/or emotional help by primary caregivers, siblings, friends and others. This help usually meant that time was taken away from other tasks and invested in the patient.

Most of the young people who took part in the study expressed concerns relating to this special treatment, helping or being helped by others. The treatment was mentioned in both negative and positive terms as participants expressed frustration and gratitude. Most participants wrote or spoke about being treated differently by people within and outside of their families.

Several participants noted the novelty of their sibling relationships due to increased dependence of patients on their siblings. One sister noted how her brother’s disability ensued her treating him differently. It often required her to take on a helping role:

“There is a different sort of brother/sister relationship than normal because [patient] relies on me to constantly help him” (Rachel, sister, age 11).

A patient from another family spoke of his dependence on his siblings for special treatment as well, noting the practical support they provided to him:

[My siblings are often]…helping me with …toilet and putting me in the chair and you know …Other brothers and sister… relationships are different 'cause they're not that close. They are close, but …they don’t take you to the bathroom. (Dan, patient, age 19)
In these cases and others, the different or special nature of the sibling relationship was illuminated by the way siblings treated each other.

A few participants mentioned the special treatment of the patient from a perspective of injustice or obligation. They noted inequality both between siblings and in terms of caregiver relationships. One sister wrote about the patient in her family as the most important one. She saw her role in the family as less special than that of her sister:

“My sister … has always been the #1 out of all of us kids. It’s kinder hard seeing that she’s always number 1. But in the end I love her to bits!” (Tamasin, sister, age 15).

Another sister noted the need for her to take on additional care giving roles at times due to the patient’s condition. Frequent hospitalisations meant that the primary caregivers were sometimes not home, so responsibilities were delegated to older siblings:

“When she goes into hospital I really have to step up and look after my brothers and sister. Sometimes I don’t want …but at the same time I know that I have to…” (Valerie, sister, age 13).

The prioritisation of the patients over the siblings was not only resented by the siblings who wrote and spoke about their experiences. The patients also generally wished that they did not require the special treatment they received:

“[Tamasin] kind of had to grow up in the shadow of me because for so long it was [Lynda] & [Tamasin] but when I got sick it was always [Lynda] then [Tamasin]” (Lynda, patient, age 17).

The patient expressed an awareness of the inequality between the way her family viewed her sister and her. She knew that her needs as a patient took precedent over those of
her sister as a daughter when she was hospitalised or when her illness required her family to give her special attention.

The patients and siblings expressed a desire for the even allocation of caregivers’ time and attention. Though equality was usually the ultimate ideal, they acknowledged that this was often an unrealistic goal. One patient felt resentment toward the circumstances created by her illness that required her mother to spend more time with her than her siblings:

When I was younger I was definitely treated different … I had to be cared for more and …It was always about me and how I had to be admitted to hospital and I felt like shit ... I felt like my brothers and sisters missed out on time with my mum because she would spend time at the hospital with me. (Lynda, patient, age 17)

The patient seemed to blame herself for the unequal distribution of her mother’s attention. The circumstances of her illness created the need for her being treated as more “special” than her siblings, which was not perceived as desirable.

Most patients expressed gratitude for the help they received from families, professionals, organizations and friends. They knew they were dependent on others and appreciated the special treatment:

My family helps a lot. My brothers and sisters get my water and meds which saves me a lot of walking. My mum and dad cook for me and my mum stays home to look after me and takes me to all my appointments, and stays with me in hospital. And when I do go to hospital my dad takes time off work to look after my siblings. (Mara, patient, age 15)
The patient was aware of and thankful for the special treatment she received from her family. She did not take it for granted or feel entitled to it. Another patient acknowledged the role that the play specialists played:

The play specialists, they brought me some stuff to do: some board games and other stuff... helped me put my feet off the bed and they took me to the toilet and they helped me to do more things. (Marisa, patient, age 11)

She was grateful for the special treatment she received when in the hospital.

The help of family members, friends and/or professionals was acknowledged in every recording, but not in positive terms in every mention. Patients appreciated opportunities to be independent and help themselves:

…the thing you should know about young people with [disease] is... we don’t like people like chipping in stuff …they can do anything themselves but when they need help they’ll say, “I need help.” (Simon, patient, age 16)

The patient mentioned that unsolicited help felt disabling. He wanted to help himself whenever possible, rather than being treated as special.

Young people generally demonstrated a desire to preserve the state of interactions before they or their siblings started receiving PPC. Those interviewed wanted to be seen as daughters, sons, brothers and sisters. Their illnesses, however, often meant that they were seen as patients or sick children requiring special treatment. They demonstrated understanding of the necessity of differential treatment within families, however, and appreciated it. There was a general acceptance of the required special treatment by siblings and patients, though they still strived for equality as an ideal.
2. *Spending time with family*

Young people involved in PPC expressed the value of their families’ closeness. Their closeness was expressed as time spent together. All of them spoke or wrote about their families in at least one part of their diaries and generally referred to their families being together as a positive goal.

Many young people wanted to spend as much time with their families as possible. They usually enjoyed family time and their families’ provision of comfort and support:

“I think about what could go wrong, what ...could happen... Things like that and how I can get through it. Being with my friends and family helps” (Dan, patient, age 19).

The patient used his family as a resource to help him deal with anxiety. Though in other parts of his recording, he mentioned not wanting to distress them by talking with them about serious things, he valued their company.

Several participants expressed feeling happiest when everyone was together and enjoying harmonious family bonds:

“I feel especially happy when my parents are happy. My mum is like happy… and my sister’s not whining. Then I know I’m not in trouble. [laughter] … I’m also happy when my other sisters are here …and don’t have problems with their boyfriends” (Simon, patient, age 16).

The patient simply wanted his family to be at peace and spending time together. He was happiest when his family members were reunited and getting along.

Overlapping with the theme of special treatment, a few young people wrote about how the patients’ illnesses had encouraged their families to become a tighter unit:
“It’s really special being [Mara’s] sister because her sickness has made our family closer and also mine and [Mara’s] bond” (Valerie, sister, age 13).

The sister found that the patient’s illness served as a catalyst for family cohesion and her relationship with her sister. Because her sister was ill, she and the rest of her family treated the patient with special care. This special treatment increased the amount of time that the family spent together, which she inferred made them closer to each other.

Young people wanted to be involved in family activities and conversations in most cases (but not always) including the care of their brother or sister patients. Several expressed fear and helplessness in regards to the patient’s disease. Spending time together seemed to ease this fear:

“I feel sad when we are not all together at home. When [Mara] is at hospital I don’t know if she is really sick and if she might die. When [Mara] comes home I will feel happy that we are all together again” (Alisdair, brother, age 9).

Brothers, sisters and patients all spoke of having their families together. This may have been linked to fears about the patients’ illnesses. Loneliness and confusion were expressed in a couple of the recordings. One sister wanted to help the patient in her family, but could not since he was away:

“Alone in my room most of the day.
Sad I couldn’t help [Richard].
Most of my normal days are like this” (Rachel, sister, age 11).

The sister expressed a desire for involvement in her family’s caretaking role of the patient. She seemed to want to be present and involved in her brother’s life. Both siblings and patients mentioned that having people around the patient was generally necessary:
“I’m afraid that she is going to get sick and nobody will be there” (Heather, sister, age 11).

Being together was not only perceived in terms of increasing family cohesion but in decreasing fears related to the patients’ illnesses. Thus, siblings and patients shared a common goal: to spend as much time together as possible and ensure the patient was well cared-for.

3. Judgment / Discrimination

Several participants mentioned the judgement or discrimination of the PPC patient by others. They perceived that others were judging them because of their illness. They spoke or wrote about individuals outside their immediate families who they felt made assumptions about them, which were always negative and often untrue.

Young people commonly expressed discrimination against patients, usually on the basis of disability. Several of them answered the question about “being a young person who is unwell” in terms of being disabled:

I’ve been doing a lot of thinking. Being unwell (sick) only affects my education but being physically disabled means more.

When I’m around people other than the ones I know well, I feel uncomfortable and embarrassed at myself because of my physical disability… I dream of having a successful future but in reality I’m in a wheelchair and how long I will live is just a question that can’t really be answered. (Dan, patient, age 19).
The patient saw her illness as a disability and a major limitation of her abilities, confidence, lifespan and future aspirations. She expressed being judged by others and uncertain of her ability to overcome obstacles imposed by her disability.

When the disability was shared, as it was in one case, discrimination was not as apparent. One brother noted being unaffected by the patient’s disability because he was dealing with the same disability himself:

“Having a sister who is physically disabled doesn’t affect me because I am physically disabled, too” (Sam, brother, age 15).

Young people expressed both pride and misfortune over the disability. They sometimes mentioned their identity incorporating aspects of being involved with disability in some way. One sister highlighted her emotions in her diary when writing about feelings relating to her brother’s differentness:

I get angry cuz people look at [Richard] differently
I get annoyed when classmates make fun of disabled people.
I’m proud to say my brothers disabled (Rachel, sister, age 11).

Her reflection could be perceived as a defensive response to the way she perceived others’ reactions to her brother. The brother patient’s disability shaped her perception of situations beyond her family environment.

One patient perceived that his physical disability affected his peer interactions. Adolescents may hold a developmental expectation for sexual contact or attention. When disabilities are visible, however, adolescent patients’ expectations may change:
I had a bad day thinking about...having a girlfriend and stuff like that… [Girls] judge the wheelchair straightaway. They look at it and they think, “He’s mental” ... They might expect that I wouldn’t want a relationship (Richard, patient, age 19).

The patient perceived that his peers connected his physical disability to a mental one. He expressed that peer females would assume things about him that were not true.

Many participants expressed concern over others’ reactions to their disabilities in relation to using wheelchairs. One patient mentioned the unexpected state permanence of his disability. The patient’s condition meant that he was in a wheelchair for weeks before returning to a walker and finally unaided walk:

“Being in a wheelchair was cool but kind of weird... You can’t step out whenever you want to. Like, ‘Oh, that’s enough, I’m going to step out now.’” (Simon, patient, age 16).

His own prejudgement determined his reaction to his wheelchair. Though he did not mention discrimination by others, his own judgement of his disability was highlighted. Another patient mentioned negative reactions from acquaintances when using her wheelchair:

“I HATE being out in public with my wheelchair because I see people that I know and sometimes they treat me differently and they have no idea what I’m going through” (Mara, patient, age 15).

The patient expressed a desire for others to treat her consistently regardless of her dependency on her wheelchair. Another patient mentioned others’ mistakenly connecting his physical disability to a mental one:
I don’t think [others] fully understand… My brain is the same as other people. It’s just my physical body is different… At school, they say mean things … they can’t say, ‘Hello,’ but they can call you names. But I don’t care. I just ignore them. Just: One ear in, one ear out. I don’t let it go there. It does a little bit, but then I push it out …They’re not as important to me as my family … Definitely, if my family says something, yeah... but when someone else says it, I don’t care. I say something back. (Dan, patient, age 19)

The patient asserted that he dealt with the discrimination by selective listening. He defended himself by paying attention to his family members and blocking out the words of others who judged him wrongly. He decided not to care and did not let criticism from those who could not be trusted affect him as much.

Young people’s perceptions of others’ judgement or discrimination arose from many of the transcripts. Most of them saw “disability” as a big part of their lives and felt that it affected the way people treated them, and generally did so in a negative direction. The young people expressed using a variety of coping strategies to withstand the often frustrating adversity, including feelings of pride and selective attention.

4. Understanding

A few young people involved in PPC expressed a general lack of understanding from others about their circumstances. The theme of understanding reflected the empathy or lack thereof toward patients and siblings. The participants knew that they were understood when their situation was acknowledged. Others within and external to their immediate families were sometimes not perceived as able to comprehend what patients and siblings were experiencing.
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Feeling understood and communicating feelings and perceptions was mentioned by several participants. They usually wanted their difficulties recognized and appreciated. One participant spoke about his gratitude toward his friends who were aware and respectful of his limiting illness:

The main thing [friends] have done is like... respecting that I have a tumour and like can’t do as many things ’cause of my tumour… I just think that they understand my tumour and ...that they acknowledge about the tumour” (Simon, patient, age 16).

The patient’s friends were able to help him by recognising his situation and his resulting needs. He, like several other participants, was unable to participate in the sporting activities that he used to be involved in. Through understanding his limitations, the patient and his friends were able to come up with alternative activities to participate in together.

A couple of the siblings expressed the desire to have their hardships acknowledged as well. Their brother or sister’s special treatment was warranted, but they expressed a desire to for special treatment at times as well:

I think people should feel sorry for the sister and brother. I was sick when [Mara] was in hospital. I had to stay home and my sister and my dad had to look after me. It wasn’t good because I couldn’t go and visit my sister in hospital. I had a tummy bug and I gave it to [patient]. It made me feel stink. (Alistair, brother, age 9)

The participant expressed a desire for the acknowledgement of his difficult role as the brother of a PPC patient. He acknowledged that he took on the position as a sick person at times, also, and perhaps wanted that understood by others.

A few participants sought the empathy of others in similar situations:
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“[My friend helped when he] talked to me. And he knew what I was going through 'cause he was. Not mentally but physically, maybe... but some aspects of mentally. And no judging” (Dan, patient, age 19).

By communicating with others in their positions, a few patients spoke about experiencing empathy. They often met others like them from camps designed for young people with their illnesses or disabilities.

Greater understanding was an issue a few participants mentioned. Some of them viewed this project as a way to voice their concerns to facilitate that understanding.

5. Mortality

A feeling of having a limited amount of time was mentioned by a few participants. Despite journals asking about “young people who are unwell,” ideas relating to impending death arose from some of the transcripts.

Most of the participants mentioned death or a feeling of having limited time. This theme commonly interwove with others such as family time and understanding. Many siblings expressed fear of losing their siblings while some patients spoke about death candidly:

“I kind of like to talk about my [disease]…It’s just something interesting in my life. I can’t pronounce the word. It’s pretty interesting that I was like an inch away from death” (Simon, patient, age 16).

The patient took a blunt approach to discussing his illness and impending death. Others wrote about their concerns relating to death which interwove with the other themes:
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“I like going to see [Mara] because I miss her. I feel sad when we are not all together at home. When she is at hospital I don’t know if she is really sick and if she might die”
(Alistair, brother, age 9).

The theme of increasing “Family time” is perceived by the participant as a solution to decrease his fear of his sibling’s death. By being around the patient, the patient’s aliveness and the cohesion of the family are verified to the brother.

The position as a “dying person” seemed to reap benefits to one participant:

“Since I was dying, I have quite a lot of… cool stuff. I’ve been on camps and stuff”
(Simon, patient, age 16).

He used the description himself, acknowledging his awareness of his limited lifespan.

Addressing death with young people is still not a simple matter, however. One participant spoke directly about the issue of knowing her prognosis:

The thing I worry about most is the dying bit. That’s what I don’t like. The doctors tell you but... you want to know the truth, but in a way, you don’t. Like stuff like that, you don’t want to know the truth. Like, I don’t. But in a way, you do... but yeah.
(Dan, patient, age 19)

Despite all being involved in PPC, not all participants noted their prognosis or that of their sibling in their recordings. The knowledge of impending mortality did not arise spontaneously from all the transcripts, but its effects were noted by several participants.

The special treatment of patients, spending time with family, facing judgment or discrimination, being understood/understanding and facing issues of mortality were mentioned by a number of participants.
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6.5. Study Three Discussion

The experiences of young people involved in PPC are rich and multifaceted. The recordings collected for this study indicate that many PPC patients and siblings want to take actions that address their concerns. Their recorded thoughts not only reflect their own affairs, as may be expected from young adults (Neff & McGehee, 2010), but those of their families. If readers can assume that the young people’s recordings reflect their real perceptions, then siblings may wish to be proactive by joining in activities with their families and participating in family matters. Young people dealing with matters relating to PPC are likely concerned about a lot more than themselves.

The young people in this study were active in their participation by the nature of its design. However, not all research aimed at helping children involves them directly. As mentioned in Section 2.3, several childhood researchers have suggested that research is a method of empowering children (Christensen, 2004b; McPherson & Thorne, 2000; Powell & Smith, 2009) while protecting and respecting them (NZ Ministry of Health, 2006a). Ethnographic studies which involve young people allow them to enter the domain of researchers and scientists who would not likely to take them as seriously in other contexts. Researchers who involve children in the process may aim to challenge the silencing of their voices in the social sciences. In this case, by discerning their needs in the context of PPC, researchers may ultimately lead them to an enhanced quality of life (QoL).

Research involving children is appreciated by more than just those who receive the results. Young people generally supported the research with enthusiastic, active participation. Once they agreed to participate, their experiences were elicited with ease. Their desires to be involved when approached by the researcher suggests that perhaps healthcare professionals
and families who avoid involving this population in decision-making (Coyne, 2008) have less to be afraid of or uncertain about.

Several themes arose from the transcripts of the young people in this study. The themes indicated that special treatment, time with family, discrimination, being understood and mortality were of concern in most participants’ daily lives. Of course, as with the study of caregivers of PPC patients (Gaab, 2011), each of the young people involved acknowledged that they perceived their worlds differently as did each of their families. One patient even said, “Not everyone is like that, but that’s how it is for me” (Dan, patient, age 19) when responding to the question. Several participants voiced a respect for individual differences.

The diaries asked participants to reflect on their own positions with the questions “What emotions did you feel today?” and “What is it like to be a young person who is unwell (or their brother or sister)?” As a result, participants often reflected on their identities when writing in the diaries. The patients generally held identities as people living with disabilities or illnesses and facing death. They are clearly affected by their illnesses and deserving of extra attention from those who care for and about them.

The identities of PPC patients and their siblings may warrant discussion either in the context of a family, the medical environment or elsewhere. Dunlop (2008) recommends that professionals react with sensitivity to young people’s behaviour with consideration to the dynamics of the families they come from. When a young person is ill, communication at the end of life may be directed in the areas indicated by the patient. These areas may include the aforementioned themes.
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**Special Treatment**

Several participants mentioned the special treatment that they or the patients in their families received. Identities described by patient participants in this study relate to the identities identified by researchers in a study of adolescents with cancer: life as a klutz, a prisoner, an invalid, an alien, a zombie and a kid (Woodgate, 2005). Their identities were shaped by their illnesses. In helping adolescents deal with the changes, Woodgate discovered that it was important for family and friends to respond to them like they were the same person, but also to give them extra consideration at times. The results of this study may support those findings. Patients mentioned needing special treatment in the form of more time with parents or caregivers, medication, and practical support, but generally wished that they did not require those things. Likewise, siblings wished that they could provide that special treatment (and often did) and acknowledged the special nature of their relationships with their ill siblings. They also sometimes wished that they were treated special, though they expressed that they did not want to sacrifice their ill siblings’ treatment for their own benefit.

Many of the findings of this study are consistent with those of Bluebond-Langner (1978). Though her thesis focused on a younger sample of children with cancer, the desires of children to maintain “normal” social roles are similar in both groups. Participants wanted to relate to others in the same way they did before falling ill, but noted the necessity for special treatment at times. Patients’ identities as individuals that needed more care than their peers warranted their perhaps indignant openness to receiving special treatment.

**Family Time**

Young people in this study generally wanted to spend as much time with their families
as possible and drew comfort and support from being with their families. Previous literature finds that chronically ill young people’s families impact them in positive and negative ways (Taylor et al., 2008). Primary caregivers’ attitudes and behaviours towards their adolescents’ chronic illnesses impact their adolescents’ own views of their illnesses. While many participants in this study mentioned that caregivers guided them through treatments, they rarely mentioned them as a source of tension or resentment that some previous studies found.

All participants, especially siblings, articulated a desire for family involvement whenever possible. Their families provided them with comfort and support by just being there. Patients and siblings used their families as a resource to help them deal with anxiety, not only through talking with them about the things that bothered them. On the contrary, some of them preferred not to talk with their families about their mortality or other issues. They just wanted everyone to be happy and together. Some siblings expressed how the patients’ illnesses had encouraged their families to become a tighter unit. The siblings often wanted to help the patients in their families and felt that the best way to do so was just by being present. Both the siblings and patients seemed to understand that having people around the patient was generally necessary. They wanted to spend as much time together as possible.

Judgement/Discrimination

Many of the participating patients or siblings mentioned discrimination on the basis of their or their siblings’ disabling illness. Young people expressed some pride, but mostly misfortune over the disability. They perceived that others were judging them unfairly. Considering that several participants responded to the prompt about “being a young person who is unwell” in terms of being disabled, their disabilities and the negative reactions they perceived that they provoked may warrant further exploration by their caregivers. Since
participants did not mention feeling judged by their families or HCPs, perhaps close family members or support workers would be able to bring up these topics with PPC patients and their siblings so that their concerns may be addressed.

Young people who view themselves as disabled (or believe that others view them as such) in a negative way may suffer from a lack of confidence in their abilities and future aspirations. They may lack confidence in their abilities to overcome obstacles imposed by disability. Since young people’s identities are likely influenced by the way they believe others see them, the judgement they feel may impact them heavily. Likewise, siblings of patients may reflect their defensive positions in reaction to the perceived discrimination. Siblings may view themselves as the protectors of the PPC patients. Since children and adolescents’ peer interactions are generally important to them (Lerner & Steinberg, 2009), their identities may be influenced by these matters. Being perceived as asexual or mentally impaired may affect young people’s developing self-esteem. Their own perceptions of how others perceive them may be just as damaging. Some patients expressed that they wanted to be treated consistently regardless of their dependency on wheelchairs or physical aids.

Most specialists would agree, as they often suggest that adolescents do not want to be defined by the diseases that they have or by their biological states (George & Hutton, 2003). Unfortunately, their perceptions of how they are viewed are often beyond their control. Ill teenagers face continuous transitions between being normal, independent, and socially-active; scholars or siblings; and regular in-patients facing severe treatments such as chemotherapy. However, our results do not intuitively reflect the concerns of nondisabled young people. Due to their perceptions of others discriminating against them, their desires to be treated as “normal” were not satisfied.
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The challenges of adolescents involved in PPC centre less on the technicalities of symptom control than in supporting patients and families as they struggle with transitioning into adulthood. These transitions may be complicated by factors beyond those expected of those not involved in PPC, including feeling judged as incapable of being involved in things they may want to involve themselves in.

Several of the patients and their siblings referred to the ill people in their families as “disabled” and brought up the issue of discrimination faced by them. They felt judged; that others made negative, premature assumptions about them, such as connecting a physical impairment to a mental one. Patients mentioned their disabilities as restrictive parts of them and viewed others’ perceptions of them as such as well. Their confidence seemed to be affected. Some siblings, however, occasionally mentioned feeling pride in their siblings’ disabilities and their connections to them, perhaps out of defence against the way they perceived others’ reactions to the patients. Both patients and siblings mentioned others’ negative reactions to them when using wheelchairs. Disability was certainly a part of the young peoples’ lives and identities.

Understanding

In contrast with the judged way young people perceived themselves as being, many of them described a desire to be understood. They recorded ideas relating to feeling that others did not understand their circumstances, which perhaps led to the above-mentioned discrimination. Siblings and patients rarely expressed empathy from others, though a few spoke positively of having their situations acknowledged. Participants mentioned wanting their difficulties, limitations and hardships recognized and appreciated. Siblings spoke of
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their roles in terms of being siblings of the ill child and patients sometimes sought understanding by talking to others in similar situations.

More projects or mediums that enable young people to express their ideas could be valuable in facilitating the greater perception of understanding that is desired by young people involved in PPC.

*Mortality*

Young people often mentioned mortality. Caregivers’ comments regarding communication at the end of life indicate a desire to protect and prepare their children (Gaab, 2011) so communicating about these topics with young people may be helpful. Many young people expressed a desire to be understood, closeness with their families and the ability to express an opinion about their or their siblings’ mortality.

Like the theme of disability and “Judgement” which arose from participants’ responses to journals asking about “young people who are unwell,” the theme of mortality was mentioned. In several siblings’ journals, it related to a fear of the patients’ impending deaths. Patients who brought up the topic tended to speak more candidly about it. Siblings’ concerns interwove with the theme of “family time,” as one sibling mentioned feeling happiest when the patient in his family was nearby. A patient seemed to see the benefits of having a terminal illness acknowledge, as it allowed him to experience camps and other enjoyable activities.

Changes brought on by serious paediatric illnesses and deaths are not all negative (Foster et al., 2011). Illnesses such as cancer may enhance young people’s awareness of their positive personal attributes, strengthen their relationships with families and friends and grant
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them material gains (Wicks & Mitchell, 2010). Benefit-finding may be common as young people at the end of life and those they love let go of what they cannot control and hold on to that which they can (Feyh, 2011). How sharing the knowledge of a prognosis affects family members’ perceived control remains to be explored.

Limitations

This study is limited by several factors. In order to maintain high ethical standards, sensitivity to participant needs took precedence over scientific inquiry. Participation by young people was entirely voluntary and all participants were monitored for signs of discomfort. Due to the small number of PPC patients in NZ, the sample size of young people is limited (N=16) and constrained by the honesty of the participants as well as patients’ illnesses, which could interfere with their expression. Symptoms such as fatigue may constrain children in critical conditions from participating.

Alternative approaches to the problem of the limited expression of children at the end of their lives include interviews, surveys, and questionnaires handed out to patients. Collecting data in a written or online format may allow for more structured, directive empirical studies, but may not be perceived as beneficial to participants. Arguably, the cost of participating to patients and families may be seen as less valuable than face-to-face interviews allowing for reflection. When a person is diagnosed with a life-limiting illness, their family may want to spend as much time with them as possible and to limit the amount of information that others give to the child about their situation. It is possible that paper or online methods, though less intrusive, may be perceived as less valuable. This study attempts to take the most beneficial approach to gathering data from children and families in the PPC system.
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Practice Implications

Care should be taken when approaching caregivers concerning talking about their children’s impending mortality as each child may feel differently about it. The theme of “Understanding” highlighted some young people’s preferences for having their situations acknowledged. That of “Special Treatment” showed how patients and their siblings know that they need to be treated differently at times, but that of “Judging” made it clear that children did not want to be seen as incapable or limited by their illnesses. Talking with youth about mortality, then, may generate more positive responses when the topic is raised by those they do not perceive as likely to misjudge them. If approached in a safe way, it may allow young people to express their views and facilitate more of the “Family time” or other activities they value.
Chapter 7. STUDY FOUR—SIBLINGS’ PERCEPTIONS OF PPC

7.1. Abstract of Study Four

The perceptions and experiences of bereaved and non-bereaved young people who have brothers and sisters with life-limiting illnesses are not well understood. Eighteen siblings of Paediatric Palliative Care (PPC) patients aged nine to 22 living in the Auckland area were interviewed. Inductive thematic analysis revealed that brothers and sisters of PPC patients expressed concerns about their siblings’ impending death and desires to be involved in their lives and care. They spoke of specific needs which may go unnoticed by their (often busy) families. Though an individualized approach should be taken in determining siblings’ needs, siblings may benefit from opportunities to be involved in conversations about mortality and the care of their ill sibling.

7.2. Literature Review of Opinions of PPC patients’ siblings

Caring for seriously ill young people and their loved ones is universal to all PPC delivery models (Foster, Lafond, Reggio, & Hinds, 2010). These loved ones are likely to include siblings. In a study which examined the clinical and demographic characteristics of patients who received hospital-based PPC consultations, 72.6% had siblings (Feudtner et al., 2011). Caring for a child or adolescent receiving PPC is difficult work for both paediatric HCPs and families. Communicating about the child’s illness at the end of life with patients and families is viewed as delicate but essential (Seigneur, 2011) to ensure that the necessary care is delivered and trust is maintained. The children themselves may feel the need to speak about their situations to adults and raise questions and worries. They may feel very lonely and
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fearful at this time. Allowing young patients to guide conversations at the end of life honours their progression and allows them to disclose or avoid the topic.

As the criteria for patients receiving Paediatric Palliative Care (PPC) include an expectation that the patient will not survive into adulthood, the anticipated death is worth considering. Thankfully, the death of an adolescent’s peer is an abnormal life crisis in developed countries (Balk, Zaengle, & Corr, 2011). Most children, especially adolescents, are profoundly affected when someone close to them dies (Shipkey, 2008). Though their perceptions and experiences of death vary according to many factors, adolescents tend to be especially affected by their family and the social systems in which they live. During the high school years, adolescents may be particularly vulnerable to a reconstruction of death-related concepts (Noppe & Noppe, 1997). Adolescent risk-taking behaviours may be linked to the death of a loved one and attachments to caregivers. The loss of a sibling at this time may threaten adolescents’ developmental needs and their coping abilities, causing them to experience a feeling of increased vulnerability and affecting their ability to form commitments (DeVita-Raeburn, 2004; Shipkey, 2008). They report feeling worried and uninformed about their dying siblings’ pain as well as other people they love (Hinds, Schum et al., 2005). The psychological distress of PPC patients’ siblings has not been addressed adequately in the literature to date.

Since no known study has been conducted to date examining the perspectives of the siblings of specifically PPC patients, studies of the siblings of children with specific life-limiting illnesses were examined. One study found that of patients who received hospital-based PPC consultations (Feudtner et al., 2011), 40.8% had genetic/ congenital conditions, 39.2% had neuromuscular conditions, 19.8% had cancer, 12.8% had respiratory issues, and
10.7% had gastrointestinal illnesses. These illnesses are named consistently in the PPC literature. The literature on other paediatric diseases indicates that siblings are affected in negative and positive ways.

In families with children dealing with genetic/ congenital conditions, parents who were able to engage in problem solving and coping were seen as having more resilient families (Hall et al., 2012). Though increased stress is associated with having a child with a genetic disability, stress does not always lead to negative family outcomes. When caregivers take a proactive approach, siblings may benefit. For example, a non-stressed parent of a child diagnosed with Cerebral Palsy stated that her daughter, the ill patients’ sibling, does not feel “embarrassed,” but often “defends” her sister. Many parents noted benefits to siblings when they appraised the child’s disability in a positive way (p. 35). There may be factors other than caregiver’s level of engagement that affect siblings’ coping and perceptions.

Siblings of children with neuromuscular conditions employ a variety of coping mechanisms (Read, Kinali, Muntoni, Weaver, & Garralda, 2012). One study of siblings of children with Duchenne muscular dystrophy, a common neuromuscular disability among PPC patients, generally accepted caring responsibilities for the patient in their family. However, they maintained balance by participating in other activities outside the family. Though they generally wanted to be included in family activities, they involved themselves in other independent pursuits. Their families were perceived as more cohesive as a result of caring for the patient, but siblings noted the inequality of their parents’ attention. Duchenne Muscular Dystrophy, unlike other diseases, develops from early childhood. This may help families cope. Siblings expressed that they coped by facing each day as it came, proactively holding back negative emotions, exercising humour and distractions, and physically...
It is not known if these findings are consistent across young people dealing with different illnesses or of different ages, cultures or other demographics.

In a qualitative study of siblings of children with Down Syndrome (which may result in gastrointestinal and respiratory issues), adolescents spoke of more positive than negative encounters (Graff, 2010) when reflecting on their experiences as a sibling. Siblings interviewed spoke of the personal impact their siblings’ illnesses; they had responsibilities including shopping, care giving, and giving medications to the patient. They mentioned feelings of worry and frustration as well as senses of mastery for being able to help their brother or sister: “I had to learn how to give shots and test blood sugars… that was really scary for me at the beginning. I didn’t want to give shots and I felt I was hurting her… It was really hard, but I’ve mastered it now” (p. 18). Having siblings with severe disorders clearly affects young people’s development and perceptions of the world.

Brothers and sisters of paediatric oncology patients may experience poor quality of life in emotional, family, academic and social domains, a loss of attention and status within the family (Alderfer et al., 2009). However, they also demonstrate increased sibling maturity and empathy. Thus, it appears that siblings are enabled, consistent with or against their wills, to develop maturity and care giving skills earlier than one might expect. Whether or not this is true across the NZ PPC population is unknown, as most of the mentioned studies were done on specific disease populations (not exclusively PPC patients) and conducted in the US or UK.

Siblings of children with serious conditions have a unique set of needs. The literature indicates that siblings of paediatric patients are at increased psychiatric risk (Barlow & Ellard, 2006; Sharpe & Rossiter, 2002), but may experience improved family cohesion,
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responsibility, empathy, and personal and emotional growth (Murray, 2002; Opperman & Alant, 2003; Read, Kinali, Muntoni, & Garralda, 2009). Siblings’ self-reported perceptions of learning about and reacting to news about their siblings’ prognoses remains to be discovered.

The present study sought the voices of young siblings of PPC patients in order to understand their needs. The purpose of the study was to identify the beliefs and concerns of young people coping with a sibling’s disease and impending death.

7.3. Study Four: Sibling Interviews Method/ Theory

7.3.1. Study Four Materials

The instructions entitled “Understanding Siblings’ Voices” were given to consenting caregivers. Those who consented to allowing their children to take part were given information sheets for their children. Following the signing of consent forms, semi-structured interviews were administered to consenting participants by the researcher in a location convenient to them (Appendices 31-34). This was generally in the participants’ homes, though several interviews were conducted in neutral locations near their homes to allow for greater privacy. Siblings were allowed the option of being interviewed in an area away from the ears of their caregivers, which most opted for. All interviews were audio recorded except one (who asked to respond to the interview questions through email correspondence).

7.3.2. Study Four Procedure

The PPC Team members, Heart Children Foundation family support people and “True Colours” counsellors spoke directly about the research with families who fitted participation
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criteria. They delivered or posted information (brochures outlining the intent and aims of the study) to them. The participants were recruited through the Paediatric Palliative Care (PPC) Team, Child Cancer Foundation, Heart Children Foundation in Auckland and “True Colours” in Hamilton, New Zealand between February 2010 and March 2011. A promotional note was also disseminated to potential participants through the Child Cancer Foundation’s “Sharing” magazine (Appendix 2). Most of the families were recruited through the PPC team, who identified them as English-speaking and within the age range and cognitive ability to be able to verbalize their perspectives.

The aims of the research were explained in the information sheet to ensure cultural sensitivity and to respect ethical guidelines. The young people were invited to participate only after verbal permission was granted from their caregivers. Ethical approval of the study was granted by the Northern X Regional Ethics Committee, reference number 4531.

Analysis

After receiving the permission of the young people’s PPC providers and family, the principal investigator met with the young people and spoke about the study. After completion of the 15-80-minute interviews, the principal investigator transcribed all the recorded data. The interviews were then analysed as a complete collection, discounting differences between the bereaved and non-bereaved siblings as well as male and female data sets and applying inductive thematic analysis (Braun & Clarke, 2006). The transcripts were stored in NVivo, a computer program for qualitative analysis (QSR, 2011). After transcription, all the interviews were read multiple times and initial ideas for repeating subjects were written down.
All quotations which related to the sibling’s experience were coded on a semantic level without interpreting the young peoples’ statements. A few of the same quotations were allocated different codes (e.g. “activities with the patient” and “communication within the family”). Other similar codes that arose from the data were gathered into potential themes (code groupings). Initial code families included “activities with the patient,” “communication within the family,” “communication outside the family,” “feeling sorry for the patient,” “helping the patient,” “hopes and concerns,” “knowledge about death,” “pride in the patient,” “wanting to be with the family vs. alone” and “wanting to be with the patient.” The themes were reviewed by checking the associations to the quotations and the entire data set, defined and labelled.

After initial coding, specific attention was paid to two of the most robust themes: participants’ knowledge about death (“The Mortality of Patients”) and involvement in the care of siblings (“Helping Patients”). During analysis of the first theme, specific attention was paid to communicating about death in relation to other Studies. Later, the themes, “Concern for Patients,” “Spending time with Patients,” and “Pride in Patients” were examined.

The themes were then analysed thematically. Repeating codes were grouped together. The coding procedure was intended to identify the subthemes specific to each data set. All participants were given pseudonyms before a Maori research companion verified cultural and methodological appropriateness by inter-coding and revision.

7.3.3. Study Four Participants

Eighteen young people aged nine to 22 years participated in this qualitative study. The participants included seven bereaved sisters, five non-bereaved sisters, four bereaved
brothers, two non-bereaved brothers. The participants came from a total of nine families. The participants’ siblings’ illnesses included cancers, heart conditions, and dystrophies.

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Table 4: Study Four Sibling Demographics (bereavement status and patient’s illness)

7.4. Study Four Results

Siblings spoke about the significance of communicating about death, the avenues through with it occurred, and the consequences of so doing. They spoke broadly about their roles and concerns and the importance of being there and caring for the PPC patient in their family. Many also spoke of being proud to be their patients’ siblings.

The Mortality of Patients

Most siblings at least mentioned the impending or past death of the PPC patient in their family, though mortality was not initially asked about in the interviews (Appendix 34). They learned about the prognosis or death through a variety of channels and expressed the outcomes of obtaining the information (Appendix 35).

Young people’s parents, doctors, or the patients themselves told most of them about
the impending or past death of their sibling. They often noticed the patients getting sicker as their symptoms became worse, but many did not fully expect their brother or sister to die in the end.

“I don’t think any of us expected her to die. I mean, we knew it could happen, but I don’t think we were prepared for it” (Stephanie, bereaved sister, age 22).

Most siblings felt it was important to discuss the impending death because it increased their understanding of the situation. The knowledge gave them a greater appreciation of their sibling, which usually resulted in them spending more time with him or her. They became more patient with and accepting of the patient and paid more attention to him or her. Several siblings mentioned feeling inexperienced and needing time to cope, prepare and seek comfort in the situation.

I prefer to know what was going on. I would hate being left out… It’s easier to cope if you know everything. If you’re left out, I find it would’ve been harder to cope…because you don’t know what’s going on or what’s happening.

[Researcher: “What should other young people know about what it’s like to be a young person with an unwell sister?”]

I suppose they should spend as much time as they can with… their sibling… because they’ll probably regret it if they don’t. And being young, it may affect them more than an older person. ’cause if they don’t understand it then they don’t realize what’s happening…. And just learning to be patient and accepting of the young person when they’re sick and realizing that they do need more attention than you, but …it’s not their fault. It’s just because the other person’s sick. And probably joining in. Like if
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they’re told everything, they know that they feel a part of it. So that they’re not left out, then they probably …deal with it better. (Stephanie, bereaved sister, age 22)

A few mentioned anger at being “left in the dark” or expressed confusion and fear on observing the symptoms without having them explained. One also mentioned that being misled and having so much hope at the end of her sibling’s life made it harder for her to cope after the death.

You don’t want to talk to somebody at school unannounced and you don’t want to be left alone, but… people should know. It’s better to know than being left in the dark… Say you walk up and say something wrong, …then you don’t know why everyone’s upset with you. I think people should tell. Even young kids should be told. It affects them. (Nicole, bereaved sister, age 22)

A few siblings also spoke about the negative consequences of anticipating their brother or sisters’ deaths. A couple said they felt nervous when their sibling went to sleep and worried that they would not wake up.

There was one time when [patient] didn’t wake up until like 3:00 in the afternoon and I was getting sort of scared ’cause I didn’t know that Mum was actually going in and checking up on him. So when I… woke up and came out, I was so relieved [laughs] ’cause I was getting a bit nervous. (Jenny, sister, age 11)

Some siblings did not want their friends to talk about the death and felt that the topic was often brought up too much, making it difficult to maintain normality. Many worried about losing the patient. A couple suggested that it was more helpful to talk about how the patient enjoys life than receiving pity or awkward sympathy.
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“We would always try to be positive when everyone was like, negative about everything. We really tried to like, make it like he was normal and he would, like, live forever” (Kelly, bereaved sister, age 11).

We always used to say that he won’t die... even though everyone around us was saying that he will and that it’s just time. We were just trying to say that he was normal and that he was like everyone else, but just like, stuck in a body where he couldn’t do anything... They just like always brought up... that he wasn’t going to last forever. (Deanna, bereaved sister, age 10)

Many participants wanted to ensure that their ill sibling was still seen as living, not dying.

Thus, siblings generally wanted to be informed of their patients’ health statuses but did not want death/ mortality to be the topic of every conversation. Most siblings found discussions about the patients’ health helpful for enabling them to make informed decisions about their behaviour. Their interactions with patients were influenced by their knowledge of the situation.

Helping Patients

Siblings of patients generally expressed the importance of helping the patient in their families. They provided practical support in the form of transporting wheelchairs; fetching medications, games, schoolwork and other things; cleaning dishes and patients’ rooms; and (in the case of several bereaved siblings) fulfilling post-death wishes. They wanted the patients to be happy, so sang and joked with them, left them alone when required, and comforted them. They helped in order to worry less, provide comfort, keep things positive and normal, and feel the joy of helping.
I always help him when he’s in the wheelchair and ...I used to help my mum get him into the shower... I helped him... ’cause normally he would get stuck between the rocks with his wheelchair and then I would have to go and get him help. (Jim, bereaved brother, age 10)

Some siblings mentioned that they were happy to help by sacrificing time with caregivers so that the patient could be looked after. They recognized the patients’ needs which were greater than their own and most expressed gratitude that the patients received extra attention.

“[Patient] got a lot more attention than me... she’s the one that’s sick... can’t get angry with that... they need attention and that to get better. I didn’t mind it, actually!” (Nicole, bereaved sister, age 22).

When asked how siblings could be better supported by others (Questions 10-12, Table 1), many brothers and sisters expressed that helping the patient in their family was helping them. Friends who visited, prayed for and stuck around patients were valued by siblings.

When asked, “What has your family/ whanau/ doctors done that has been helpful for you?” one sibling replied,

“Be there when I’ve needed them and showed love to me and my brother” (Elise, bereaved sister, age 17).

Most siblings wanted to help as much as possible. They also expressed special gratitude for the help that patients provided to them, which was both practical and emotional in nature. Being informed about the patients’ health statuses was as concerning to many siblings as knowing how to help them. In response to, “What else would be helpful for you or for other
young sisters or brothers like you?” one responded,

More support and understanding… like what’s wrong when they’re still with it… I
didn’t really have time to make sense of it. I had to just… deal with it… We didn’t
really expect it. They could’ve helped us to... just to... help; how to help your sister.
These are some things that might help her and things not to do ’cause it makes her get
sick or something ‘cause for the first time we had to just figure it out by ourselves.
(Jack, brother, age 9)

Being included in the provision of care to patients was important to most siblings.
They all took opportunities to be involved in their lives and care.

“[It is helpful] that we can do jobs for people when they are sick and... Get them what they
want and get them what they need” (Brian, bereaved brother, age 14).

Helping PPC patients helped siblings cope with having a sibling involved in PPC.

Concern for Patients

Siblings’ helping behaviour was often fuelled by a concern for the PPC patient in their
families. Though most siblings wanted to be a part of caring for their sibling, they often
found witnessing their discomfort difficult. Several spoke of negative feelings experienced
when watching siblings suffer. Patients’ pain was a major concern for siblings.

The tough part was seeing... her suffer... We watched her deteriorate right until the
end; that was the hard part: watching her lose her dignity... I didn’t like seeing...
’cause I knew she never wanted to go like that, but you couldn’t help it. (Stephanie,
bereaved sister, age 22)
When he was sick I would worry that he may be in pain. But it was under control” (Elise, bereaved sister, age 17).

Thankfully, all siblings of participants were receiving PPC during the time of the interview or the time leading up to their deaths, so their pain was being managed. Several siblings still expressed helplessness, however, in terms of aiding the patients.

“It was really hard watching a child be like that and it’s really heart-breaking ’cause... you feel so sad all the time when you see him and you just didn’t want him to have all that pain.” (Kathi, bereaved sister, age 19)

The lack of normality was mentioned by about half of the siblings interviewed. They wanted their brothers and sisters to be able to participate in teenage activities the siblings and their peers were used to.

“Seeing her in hospital is hard. We can’t go to the mall like normal teenagers... Just hanging out with friends... Yeah, seeing her in pain and stuff. [cries] It sucks” (Rebecca, sister, age 13).

“[The toughest thing about being a sibling was] knowing that you won’t get to do as much stuff as you would with other people. Like with other little kids. Knowing that he won’t be like the other kids” (Deanna, bereaved sister, age 10).

Disability and pain were two of the biggest worries of PPC patients’ siblings. They wanted to maintain the sibling relationship and participate in the activities they enjoyed with the patient, who was often not capable of so doing.
When asked what was difficult about having an unwell brother or sister, most siblings spoke about the difficulties their brother or sister faced rather than their own. They may have experienced feelings of guilt or discomfort as a result of their siblings’ disadvantages.

Asking, “What was your least favourite thing about having an unwell brother?” often elicited selfless responses:

“That he couldn’t walk; he couldn’t run. Like, he was in a wheelchair. Normally, he would love to play rugby all the time and now... it made me feel real sad” (Jim, bereaved brother, age 10).

“He couldn’t like ride a horse or go on a motorbike or anything or... do any of that stuff or go for a proper swim or anything” (Kelly, bereaved sister, age 11).

Siblings were aware that patients’ impairments not only affected their abilities to participate in fun activities, but in completing daily tasks as well.

“She couldn’t ...get water and medicines and what she needed to do to get ready for dinner, like plates and forks.” (Brian, bereaved brother, age 14)

“Sometimes when he’s trying to do something, you need both hands and he tries to do it but... it’s hard, so he usually asks me to help... That’s some difficulties” (Marilyn, sister, age 9).

Siblings expressed negative feelings as a result of their siblings’ impairments. They may have felt guilty over the differences between their and their siblings’ physical capabilities. They were concerned about patients’ emotional and physical wellbeing. They were aware of their vulnerabilities and limitations, sometimes resulting in one case from an accidental experience.
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“I went to Rainbow’s End and [patient] has never been there. When he was younger he always wanted to go... I feel... the opposite of jealous... because he never got to do those things. And that’s probably the most annoying” (Jenny, sister, age 11).

“I didn’t know that [patient] had a sickness and I was playing with her and I accidentally hurt her, because her bones were kind of weak because of her sickness, I think, and it hurt her” (Lester, brother, age 10).

Despite acknowledging the hardships faced by having an unwell sibling, a couple of siblings expressed gratitude for their siblings’ uniqueness. Their siblings’ different abilities were a part of what made them exceptional.

“He never was able to enjoy what everyone else could. That was really hard. And just wanting him to be a normal baby. But then, he wouldn’t be [patient] if he wasn’t like that” (Kathi, bereaved sister, age 19).

Siblings mentioned many concerns for their siblings’ conditions and states during their illnesses. The injustice of disease often made it difficult for siblings to see the patients in pain and brought about feelings of guilt and pity. However, they still generally wanted to be involved in their lives as much as possible and honoured their unique qualities.

Spending time with Patients

The importance of time was spoken of by the majority of siblings interviewed. They were usually aware that the PPC patients’ time was limited and wanted to spend as much time with them as possible. They wanted to be present in patients’ lives for as long as they could.
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“I chose not to go to uni for the last three years... I didn’t want to go [away]... I used to just sit in the room and talk to her and watch TV and stuff. Just being there for her” (Nicole, bereaved sister, age 22).

A few siblings mentioned the inconsistency of patients’ physical and mental states. They adapted to the situation by capitalising on opportunities to engage with patients, but most still mentioned the difficulty of the situation.

Getting to see our sister all the time [would be helpful]. But we can’t, so... We used to see her every day. But we only see her in the afternoon or sometimes the next day or next week ’cause she’s in hospital. We get turns to spend time with her... We talk to her, ask her how she is. (Jack, brother, age 9)

Like, one week, she was healthy and the next week, gone. Like, paralysed from there [points to waist] downhill. She wasn’t remembering anything. And then you can’t spend much time with her because she spends most of the time sleeping. And then when everyone comes around, they take up her time and by the time you get in to see her, she’s just asleep, so you can’t really talk to her or anything. That was the hard part. (Stephanie, bereaved sister, age 22)

Some siblings mentioned the unavailability of other family members when they were caring for the patient. They clearly valued time with family.

“[The toughest thing about having an unwell brother was that] I didn’t get to see him much and I didn’t see my mum much” (Megan, bereaved sister, age 14).

“It’s quite hard ’cause I don’t really get to see him much and play with him much... ’cause he would always be at the Auckland Hospital, getting surgeries and staying there and we lived [far away]” (Jim, bereaved brother, age 10).
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One sibling spoke of the limited time she had with her brother and her desire for more information, which may have resulted in her spending more time with him.

I hadn’t been around. And ... all busy... with my own like social life and stuff... When you’re young, you don’t really think that... a little baby is going to pass away... Whenever I went and seen him, it was always special. I would have liked to have... known a little bit more ’cause ...It’s important ... because you should be able to spend more time. (Kathi, bereaved sister, age 19)

Most siblings wanted to be there through the tough times. They wanted to be involved not only in helping their brothers and sisters, but in sitting with them through their discomfort. When asked, “Would you rather not see her in hospital and see her in pain or would you rather be a part of that?” one sibling expressed the value of being present:

“Being... part of it ’cause... if everyone’s there, it will make her feel stronger. Like, it will help her if she feels better, like when we go in hospital ’cause when she’s not asleep, she can talk with us” (Rebecca, sister, age 13).

Several siblings acknowledged the value of being able to support patients socially. They expressed wanting to be present with the main goal of providing social support.

“We usually have time [with patient] when we sit by her and we just ...talk and laugh and then when our parents come in we pretend we’re sleeping so we can stay up and... It’s pretty cool” (Erica, sister, age 14).

Besides sharing fun times with patients, siblings wanted to be there to protect them:

We don’t know when we’re going to die, so it might be his last day... I just... try and stay near him and if...a bad thing is like going to hit him, I try and keep him away from it, but he’s usually the one trying to get us in trouble. (Marilyn, sister, age 9)
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A couple of siblings alluded to distress resulting from distancing themselves away from patients. They were particularly interested in situating themselves near patients during the time of death.

When she gets sick I feel like crying because I never know if she’s going... go to hospital... She has to have an operation soon, and I think it’s going to be on a school day and I won’t be able to go and I don’t know if she’s going to... survive it. (Annie, sister, age 11)

It [death] actually might happen at any time. And if something goes wrong, like in New Zealand, that we might not be there for her ’cause sometimes I’m like, I might go [away from Auckland] by myself ...and something might be wrong with her. And... I won’t be there. (Lester, brother, age 10)

Pride in Patients

About half of the siblings interviewed mentioned feeling proud for their siblings who were ill. They expressed admiration for their outlooks which were both related to and separate from their illnesses.

[Patient] always had a positive attitude. When she became paralysed towards the end, she didn’t care about not walking. She said she could help people who are like her, paralysed. She knows what they’re going through, so she can help them ... She always said that [disease] is not going to beat her... She stayed positive right throughout... She fought to the very end. (Stephanie, bereaved sister, age 22)

They were proud of their attitudes as well as their initiatives. They expressed gratitude for their interactions with them.
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“My brother takes me out to the movies and I’m sure most 18-year-old brothers would never do that with their little sisters” (Jenny, sister, age 11).

“You could tell he could understand you because, he was... bright. Well, we thought he was like, really bright” (Deanna, bereaved sister, age 10).

All siblings interviewed spoke of patients as very special individuals. Every participant mentioned several good qualities about each patient.

“He was very popular... He had lots of friends and all that” (Jim, bereaved brother, age 10).

He’s got the cutest smile and ... even though he was sick, he was so happy... He would laugh... especially like when he was getting better. He used to give this happy little smile with his eyes... He pretty much just brought peace to everyone. (Kathi, bereaved sister, age 19)

The siblings were grateful for their roles in patients’ lives and acknowledged their strengths despite their difficulties.

“She’s cool...She helps me with my homework... She’s really good at games... She’s better than me! [laughs]” (Jack, brother, age 9).

Brothers and sisters spoke positively about patients in the interviews. PPC patients were major parts of their lives. Siblings valued information about and time with patients and spoke of concerns for and pride in patients.

7.5. Study Four Discussion

Though each young person interviewed held different perceptions of their situations,
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backgrounds and issues, “helping” and “mortality” themes arose the most consistently. The young people in this study indicated that their involvement in helping the patient and awareness of their mortality were generally important to them.

Communicating about the end of life is important to families, as caregivers’ comments regarding helping indicate a desire to protect and prepare their children (Gaab, 2011). Caregivers may be able to prepare children by addressing support and health status topics with them (Richmond & Colman, 2009). Caregivers who are apprehensive about sharing about those topics may take note: being involved in the patient’s care and conversations about their general health status were expressed in mostly positive terms by the siblings interviewed. The consequences of talking to siblings about sensitive issues are likely to outweigh the costs of remaining silent. Though siblings talked about mostly satisfying experiences with their families, several complained about the negative experience of being kept in the dark.

Young people, like adults, grieve in many different ways. Patterns of grief are expressed differently in young people than adults (Williams & Merten, 2009). Anticipatory grief may not only be expressed in the emotional, expressive fashion that one might expect. They might instead take another pattern that fits their own coping skills better. Perhaps by engaging in helping behaviour, the young people interviewed were being instrumental (Martin & Doka, 2000) in their anticipatory grief. In order to fill young people’s cognitive and active coping styles, caregivers may involve them in the care of their siblings. Open, transparent, directive instructions on how siblings of PPC patients can help their families, especially their sick brothers and sisters, would probably have been appreciated by the participants involved, who valued being helpful and involved.
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The qualitative framework which grounds this research limits its scope. The sample of participants is small and not necessarily representative of the population at large. Qualitative studies can be highly context-specific (Thomas, 2011). The children came from a variety of specific ethnicities, cultures, ages, and genders and sibling disease types.

It should be noted that children may know more than we think about their or their siblings’ prognoses. As in the case of bereaved sisters Deanna and Kelly (ages 10 and 11), siblings may see their roles as the protectors of their ill sibling’s Quality of Life. Siblings may act as if nothing is wrong in order to keep things “normal” for the PPC patient.

This study is limited by several factors. Recruiting siblings of PPC patients is challenging due to the small population in NZ and the gatekeepers involved. In order to maintain high ethical standards, sensitivity to participant needs took precedence over scientific inquiry in this study. Participation was entirely voluntary and the permission of potential participants’ medical team or supportive organization was sought before that of their caregivers’. If both gatekeepers consented, the child was asked to participate. Most of the young people agreed to participate once the researcher reached this level, but several preferred not to be involved, so were excluded. All participants were monitored for signs of discomfort. None of the participants asked to stop the interview or remove their information from the research.

It has been stated that children should be empowered through research (Christensen, 2004b; McPherson & Thorne, 2000; Powell & Smith, 2009). Their voices should play a main role in the construction of their identities in the social sciences in order to improve the quality of care delivered to them and their families. A quantitative study of young siblings of PPC patients’ desires and wishes (including that of being involved in caring for and conversing about their sibling) may enable practitioners to meet their needs more efficiently.
Chapter 8. CONCLUSIONS

8.1. Summary of Research and Outcomes

With the aim of exploring topics around communicating with children about death and illuminating the experiences of those involved in PPC, this research generated interlinking themes. The four studies conducted demonstrated a degree of convergent validity. Overall, an aim was to gather complementary data, which arose from the results. Complementarity was observed between the three qualitative and one quantitative method; among the adult, adolescent and child participants who were well and unwell; and at the four separate (but overlapping) times of data collection. It is to be hoped that the results will increase caregivers’ knowledge about communicating with children at and about the end of life.

Preparation and Protection: More than One Way

Families/whanau generally aim to prepare and protect each other. Though parenting clearly involves protecting children, it may be less obvious that some young people also protect their primary caregivers. It is apparent that this happens in some families including those of dying children (Bluebond-Langner, 1978). The goal of protection may be shared. Young people may manipulate situations to protect their primary caregivers. The families of the PPC patients we studied mentioned wanting to spend quality time together, be seen and understood as “normal” members of society, and be involved in supporting each other around coping with prognoses and other matters.

Caregivers gave several reasons for their choices around communicating about death or avoiding the topic. Most caregivers communicated with their children about their
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prognoses to prepare their children. At various times, however, many also avoided the topic to protect their children. Young people expressed some concerns about the mortality/impending death of the patients, but also spoke of the special treatment they received including judgment or discrimination faced, being understood or understanding, and involvement in their families’ lives and patients’ care.

Primary caregivers are as diverse in their approaches to parenting as their children are in development and attitude. Like parents of healthy children, most of them have the same ultimate goal of fostering healthy development. Obviously, caring for PPC patients presents special challenges. In alignment with the goals of PPC, primary caregivers also aim to keep their children comfortable. The participants in “Study One” (of healthy children and their caregivers) may be likened to baseline participants. Though not randomly selected, the sample represents a group of “normal” young families in New Zealand. Though many PPC illnesses are congenital, one might assume that most caregivers do not expect their children to develop terminal illnesses. It is probable that many have not even heard of PPC before. It is possible that well-intentioned doctors and other HCPs may believe that primary caregivers are able to predict accurately what their children know about death, yet this may not be the case. By reflecting on the experiences of these caregivers of healthy children and their perceptions of their children, medical professionals may approach families more equipped with knowledge of some challenges they are likely to face.

Young People’s Mature, Developed Understanding

Themes within and between participant groups were closely related in many ways. Primary caregivers in “Study One” tended to underestimate children’s scores on all the subcomponents of the death concept suggesting that even health children have a fairly accurate, complex understanding of death and how living processes cease. They misjudged
their children’s abilities to accurately answer questions about “causation” when asked how their children would answer the question, “Can you tell me something that might happen that would make someone die?” and “When _______ happens, why does that person really die?” (Appendix 3). The concept of causation is not likely to be innate: one may not innately know the biological processes (lungs stop breathing, heart stops beating) associated with death. Other studies suggest the development of this concept may be influenced by the child’s school, the media and other sources mentioned in the introduction. Study One caregivers’ underestimations of their children’s scores of this concept (causation) and others may be inferred from visual analysis of the comparison scores. One can then perceive that children are likely to know a little more about death than their caregivers think they do. Though they occasionally mix up concepts (i.e. “cars die,” “light bulbs die,” etc.), these are likely due to euphemisms or other unclear messages they receive through the evolving environment which includes increasing media-transmitting technology (i.e. “people die because they get squished,” etc.). Reassessments of young people’s understanding of death will allow psychological research to keep up with child development in our increasingly globalized society.

If healthy children as young as five to seven years of age have mostly accurate perceptions of death, it is likely that their unhealthy and older counterparts (such as those who participated in Studies 3 and 4) are even more understanding of these issues. The PPC patients and siblings involved may be more aware of factors that could affect their mortality.

The Difficulty of Communicating

Considering the taboo nature of death, the general dislike of breaking bad news and the perceived vulnerability of children, it is apparent that communicating about death is difficult. Children expected to die before their family members may be seen as even more
vulnerable. Coping with prognoses is the first issue families must address. It is not surprising, then, that caregivers expressed a variety of responses when asked their reasons for communicating about death or avoiding the topic in “Study Two” (primary caregiver interviews). Most caregivers spoke with all or some of their children about death at some stage during their time receiving PPC but delayed communication. It is not known how these caregivers or other caregivers would be affected by the knowledge of their children’s advanced awareness of their mortality, though past research suggests they may be more likely to regret not telling their children (Kreicbergs, 2004).

Primary caregivers who avoided speaking with children about death indicated reasons related to protecting their children. They wanted to avoid negative changes in relationships, emotions and perceptions. They worried about telling their children in the wrong way, forcing them into unwanted discussions, or dishonouring others’ recommendations. They did not want to upset children, bring up the unknown, provoke negative stigma associated with illness, or make them lose their innocence. However, some of the young people’s responses only marginally reflected those of their caregivers.

Unsustainable Avoidance and the Permanence of Telling

Since most primary caregivers who avoided talking with young people about prognoses eventually spoke to them, their reasons for avoidance are worth consideration. Caregivers in a different study who avoided speaking with terminally ill cancer patients and did not regret their decisions were those who believed that their children did not know what was going on (Kreicbergs, 2004). This reason may be sustainable with patients, but is unlikely to be suitable with siblings for very long. They will eventually find out after their siblings die. Not being told about a sibling’s prognosis could lead to guilt, anger or a loss of trust. Siblings may want a chance to say goodbye or take care of unfinished business with the
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PPC patient. Primary caregivers’ desires to protect their children’s emotions, perceptions and relationships may only be justifiable when pertaining to conversations with PPC patients.

Such a perspective was reflected in caregivers’ comments when talking with PPC patients and their siblings. One caregiver reflected on her tough decision: “It’s a one-way crossing... You can’t say, ‘Oh, didn’t you want to know that?’ [Patient] gave hints that he did know, but didn’t want to go there... I didn’t want to change [friends or family], walking around, looking like a funeral” (CASEY). The caregiver wanted to be sure that disseminating the news of her son’s prognosis did not affect the way others acted around him. She was concerned that the information could change others’ behaviour in a negative way.

*Normal Kids want to be Special; Special Kids just want Normality*

Just as caregivers were concerned that telling children their prognosis would change the way they were treated, young people expressed concerns over their own special treatment or that of their patient sibling, thus validating some of the reasons caregivers chose not to speak with their children about death. The hospice “Very Special Kids” in Melbourne, Australia, is so named to reflect the way families see the child in their family who is receiving PPC (personal communication, Gail Hessell, 2012). Participants from Studies Two, Three and Four expressed comments indicating that they were aware of the uniqueness of the patients in their families and generally wanted to protect them.

Many participants wanted to ensure that the PPC patient in their family was still seen as living and not dying. They wanted to prepare themselves and their children for what was ahead, but did not want the news to affect the way they acted or were treated. It has been said that children who are “normal” want to be treated special and “special children” want to be treated normal. Primary caregivers, ill children and their brothers and sisters involved in PPC
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seemed to understand this situation quite well. Most caregivers carefully examined the situation and tried to bring to light how much information their children wanted before passing on information. For children who do not express their concerns to caregivers, research like this may give caregivers and HCPs a little more insight based on other families’ experiences.

This theme of maintaining normality by avoiding the topic of death was triangulated not only across studies (Bluebond-Langner, 1978) and cohorts, but across participant groups and families. Siblings who act as if nothing is wrong may not be in denial of the PPC patients’ prognoses. Siblings from another family who participated in “Study Four” (sibling interviews) spoke of their roles as the maintainers of normality: “We always used to say that he won’t die... even though everyone around us was saying that he will... We were just trying to say that he was normal and that he was like everyone else, but just stuck in a body where he couldn’t do anything... They just like always brought up... that he wasn’t going to last forever” (Deanna, bereaved sister, age 10). Many siblings wanted to be able to get on with their lives without having to focus on their siblings’ impending death all of the time. This triangulates nicely with Koocher’s (1981) relation of paediatric oncology patients to the “Damocles syndrome.” The syndrome is a state of long-term uncertainty, stress and anxiety experienced by paediatric patients and families treated for leukemia, since only about 50% are usually cured and less than ten percent are successfully treated. Damocles syndrome may be defined by continuous reminders of unpredictable, anticipated death that may bring about stress and anxiety. The syndrome may apply to more than just siblings, as Koocher relates it to children with terminal illnesses, their families and their HCPs.

Though families see their child as “special” and honour their position, young participants who were unwell mostly wanted to be seen as “normal” (in “Study Three” of
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young people’s diaries). Their healthy brothers and sisters generally understood the reasons for special treatment but saw it as an inequality. Whilst most (especially older) siblings said they did not mind sacrificing certain things (such as parents’ attention) if it was helping their sibling patients, the PPC patients themselves were often especially frustrated with this. Patients sometimes viewed the special treatment as a form of unintended discrimination within the family. Though brothers and sisters did not express viewing it this way, they were also concerned with discrimination against the PPC patient outside the family. Sometimes the patient’s illness was not even called an illness by siblings, but referred to as a “disability.” Perhaps caregivers’ are concerned about differential treatment as a result of disclosing prognoses. If so, their concerns may be valid. Normality is something most children feel the need to strive for, regardless of knowledge about prognostic information.

Talking as a way of Normalizing

Primary caregivers who spoke about death with their children did so in reference to preparing them. Sharing information may be a means of enabling children to cope more successfully (as reflected on in many caregivers’ interviews). Information facilitates an understanding which parents may hope will translate to emotional comprehension and processing. Though learning about illness and prognostic information may not normalise PPC, it may allow the young people involved to justify the actions being performed by others around them. Being understood was another major theme arising from young participants’ diaries and interviews. They felt that others judged them prematurely because they did not know what it was like to “walk in their shoes.”

Considering the prevalence of speech about keeping things normal for children, this theme deserves further attention. Given the low response rate of CGs who consented to their families’ participation in Study 1, one could also argue that all of my studies reflected this
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theme. Thus, the theme of “maintaining normality” might be seen across each of the studies conducted. Talking about death with children is not likely considered a “normal” activity for primary caregivers to discuss with their children, though children’s thoughts about the impending death appear frequent.

*Helping One’s Own Family*

Though siblings understood the special needs of the patient, time with family was the greatest desire that they were unwilling to sacrifice. Likewise, patients expressed feeling happiest when reflecting on times spent with family members in fun or peaceful settings. Being with their family was the most robust theme across and within all participant groups. Despite differences in religion, age, culture and disease, family was a major priority. This is consistent with the results of other studies which advocated for “family cohesiveness” as an attribute which helped children adapt to the death of a parent (Christ & Christ, 2006). All families shared the common goal of keeping the patient comfortable (or, in the patients’ cases, maintaining harmony in the family). Studies to test interventions mediated families’ education about the disease and “how to help” or “how to let patients help you” may be used to greater explore this theme.

Another profound theme that arose spontaneously from the data was that of “helping.” Though the importance of patients creating a legacy (Steinhauser et al., 2001) has been highlighted by past research, the act of helping as a process rather than a means to an end is not widely explored in the literature. The theme of helping others (family members and those in the community) was observed in all the studies conducted, though the studies did not set out with the goal of obtaining information about helping behaviour. Even nonparticipants in “Study One” (of healthy children and their caregivers) addressed their desires to help with this research.
Several primary caregivers who participated in “Study Two” spoke often of how important it was for their children to be involved in the care and helping of the sick young person. They wanted to help their children help each other. Many of them were parents of adolescents. Interdependence and helping may be at conflict with the common theory that those in the period of adolescence strive for independence (Woodgate, 2005). In “Study Four,” however, more siblings mentioned concerns about spending time helping their ill siblings than doing things independently. Primary caregivers generally weighed the responsibility of keeping a child’s prognosis to themselves with the cost of sharing the responsibility or weight of the information with patients and their siblings. Caregivers who told their children did so in order to help them cope with the news, whether through direct conversations with them or allowing them more time for anticipatory grief. In either scenario, primary caregivers only wanted to help their families.

The desire to help others interwove through each study. Several primary caregivers of healthy children who decided not to participate in “Study One” because of personal circumstances acknowledged the value of the research and apologised for not being able to “help other families.” In “Study Three,” patients expressed wanting to help their families by involving themselves in family and other activities. One patient gave her “Make a Wish”™ opportunity to her sibling when she fell ill and reflected on the situation with an entirely positive outlook. She did not mention anything about hoping for special treatment from her family. She only seemed to hope for mutual reciprocity, participation and sharing. Several siblings mentioned the help their brother or sister provided, including helping with homework, daily tasks, chores and fun activities. A couple mentioned how much they loved “cheering up” their siblings. Mutual altruism was a major process implied in several stages of this research.
Helping beyond One’s Own Family

The helping behaviour stretched beyond nuclear family relationships. More than half of the patients and siblings who took part in “Study Three” took an active voice in advocating for those with disabilities in their diaries. They wrote about the injustice they or their siblings faced and how annoyed they were with people for treating them differently. Likewise, in “Study Four,” one sibling mentioned how she bought a pen from a man who was selling them to raise money for the disease her sibling had. Most families opted to help others through participating in research. This finding supports the suggestion that children and parents’ desires to participate as a way of benefitting others should compensate for researchers’ concerns of burdening them (Hinds et al., 2005).

Protection, helping and family themes interwove with the participants’ discussions of their experiences with and beyond sharing prognostic information and talking with young people about death. It is clear that participation and involvement in care is desired by most members of families involved in PPC who participated in this research.

8.2. Directions for Future Research

In its holistic approach, PPC contrasts starkly with most of what medical schools teach. “We need to take a step back, because somewhere we lost the perspective,” recalls one HCP, “We were dealing with a child that we had divided into arms and legs, livers and lungs, heart and kidneys, and what was going on in his head, but we had lost the perspective on what was going on with the child” (Bearison, 2006, p. 170). Another HCP agrees, “Physicians are not clinicians any longer; they’re technicians”.
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The sensitive area of children’s end-of-life care is a relatively new field (Steele, Davies, Collins, & Cook, 2005). Ethical concerns in end of life research include the vulnerability of participating families. Children may be unaware of their deaths and parents may not as yet have come to terms with their situations (Tomlinson et al., 2007). In addition, logistical issues exist. Arranging meetings with children with terminal illness and their parents may be challenging between physicians’ appointments, work, and siblings’ activities. Fatigue, a common end of life symptom, may also limit times for meetings. However, without researching PPC, we may be discriminating against this population, depriving them and future families and patients of the benefits to be sought.

Researchers who embark on projects in the field of PPC may perceive a number of gatekeepers between themselves and their potential participants (Tomlinson et al., 2007). Though the gatekeepers (HCPs, Ethics Committees, parents and families) are indeed concerned about protecting themselves and their children, they are also likely to be grateful for the ears of the researcher. The most profound theme that arose spontaneously and unexpectedly from all four of the studies conducted was that of “helping.” Caregivers, PPC patients, siblings and both healthy and unwell families participated in research with the intention of improving others’ lives. Not only did most participants mention wanting other families to learn from their experiences, they often wanted the involvement of their family members to contribute to their own growth. They expressed a love for learning and teaching within and beyond “whanau,” (Metge, 2001). It is likely that they perceived their whanau as more than just “a family group composed of parents (plural) and children... contained within one household” (p. 19). They wanted to use their insight and mistakes to help others. This desire to help others through sharing information may warrant further investigation. The theme of helping was prevalent in more than instances when participants spoke of their
reasons for participating in research. Primary caregivers of PPC patients spoke with their children about death to enable them through understanding. They avoided the topic of death to help children cope with stressors by normalising the situation. Even several parents of primary school children in healthy families who chose not to participate in the study wrote comments about how they would like to help but could not at the time. Young people who participated in the diary study mentioned wanting to be as involved as possible in their families’ lives by participating in the special treatment of their siblings (even patients wanted to help their siblings and did so) and acting as activists on behalf of disability causes.

“Helping PPC Patients” was one of the major themes that arose from the sibling interviews as well.

The qualitative studies opened areas worthy of additional investigation. Further research may explore how the outcomes relate to the general population. More focused qualitative and quantitative studies may examine the themes raised. A more directive study of young people’s social and emotional wishes may enable PPC practitioners to care for families more efficiently. A conceptual model has been included (Appendix 36) to illuminate themes which emerged from triangulating the four studies. One must avoid making broad generalisations in interpreting this depiction of themes and instead look at the model as a basis for further exploration through research.

Though uncommon before, (Lo, 2004), advance directives are now included in the rights of children with life-limiting or life-threatening conditions, young people and their families to education and counselling in NZ (National Health Board, 2011). More research into how caregivers approach this sensitive area with children may be of practical value in enabling practitioners to efficiently meet their needs, such as the needs identified in these studies.
PPC researchers have a long way to go. Effective PPC must be grounded by quality education to HCPs and supportive public policies (Field & Behrman, 2003). At present, these are not grounded in an adequate pool of data. Several questions remain unanswered concerning how children with terminal illnesses function in the systems set up for them. How are hospitals, hospices and home-hospice services recruiting appropriate clients, addressing their psychological and spiritual needs, and supporting them in the best way possible? How might parents support their infants, children and teens through the dying process? There may be a “need to communicate with the dying infant” (Bearison, 2006, p. 167). How can we address this issue? How are physicians affecting children by filtering the information through their parents? How do those involved disclose and deliver information in considerate, respectful ways? What roles do and should an individual play in enriching the last days of a dying child?

Unfortunately, the literature is limited surrounding children’s understanding of death and disability, parent and sibling interaction, and the emotions of children during the dying process. Much research is needed to steer future practitioners to a more appropriate approach to providing comfort to children. Most of the caregivers who declined to take part in “Study One” wrote about how unprepared their children may be for the interviews due to their ages and stages of development. It could be that caregivers fear that involving their children in such a research process is damaging. It seems more likely, however, that the taboo nature of death or its socially-constructed, frightening connotations contribute to their decision to refrain. When do caregivers believe their children are developmentally-mature enough to be allowed to speak about death? If the timing is “too soon,” what are parents waiting for?

Research addressing these questions may be able to lay a foundation for addressing
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caregivers’ fears and enabling them to prepare their children for unavoidable death conversations.

Many researchers have advocated for empowering children through research (Christensen, 2004b; McPherson & Thorne, 2000; Powell & Smith, 2009). They argue that children’s voices should play a main role in the construction of their identities in the social sciences. However, these voices are quiet in PPC research. A quantitative study assessing young PPC patients’ and their siblings’ desires and wishes (including that of being involved in caring for and conversing about their sibling) may enable practitioners to more efficiently meet their needs. In respecting the holistic approach of care delivered in this area, children’s perspectives may be framed within the context of their families.

8.3. Limitations

Though the limitations of this research has been stated in the conclusions of Studies One, Two, Three and Four, it should be further noted that this research is highly context-specific and restricted in scope. As stated in the introduction, participants came from Auckland, New Zealand, a diverse area in terms of culture, religion, demography and other factors. The topics of communication, child-rearing and death practices are likely to vary between and within families of these various backgrounds, further justifying the need for mixed-methods including qualitative research.

One of the most challenging barriers to accessing information from families receiving PPC is the need for sensitivity in approaching families. The families who may have provided the richest information (those who never spoke about death) were also the least likely to be
Perceptions of Life and Death in Paediatric Palliative Care

recruited, since they were likely the least communicative or open to conversations in the first place.

8.4. Possible Implications

*Increasing Communication*

With adequate understanding of and communication about potential PPC issues, caregivers may enable children to face the end of life with less physical and psychological discomfort. This, in turn, may facilitate the anticipatory grief and coping of their surviving family members. Research is the first means by which we may understand these perceived issues. The goal of PPC is to increase children’s QoL by allowing them to live fully and meaningfully even in the acceptance of an inevitable death (Papadatou, 1997). Before attempting to resolve issues that could diminish PPC families’ QoL, it is useful to understand how families perceive and deal with them.

*Helping Caregivers Understand Child Development*

In “Study One,” most of the caregivers who declined to take part in the study offered reasons they classified as “personal” for declining to participate. They wrote about their children being “too young,” the timing of information about death being “too soon,” and their fears of “irreversible damage.” If a child is too young to speak about death at age five, six or seven, then when are they developmentally-mature enough to be allowed to speak? If the timing is “too soon,” what are parents waiting for? These two questions may have specific answers (which warrant future research), or they may be rooted in caregivers’ fears about irreversible damage. Perhaps caregivers themselves have not had time to process their children’s prognoses for themselves.
Providing Resources to Caregivers

If caregivers’ fears about irreversible damage are the reason that they avoid exposing their children to death talk, then clinicians, counsellors or others may be able to help. Books and practical conversation-starting tips may be of use to primary caregivers. Just like sex, death is not an easy topic to converse with young people about. Since most of the current literature aimed at facilitating conversations about death targets grieving families, it may be helpful to establish protocols for death education with younger people before they encounter death through life experiences.

Perhaps death could be made a part of school curriculums to aid children’s questions about it. Some researchers suggest treading in this area with caution, though, as death education is most effective when offered over time as students mature and gain experience with death rather than as a “one-shot effort” (Durlak & Riesenberg, 1991). To enable this progressive understanding of death, primary caregivers may be the best teachers. When informed of how to go about talking with their (healthy) children about death as a biological event, primary caregivers may be able to help their children overcome fears and strengthen communication within the family as a whole. It has been suggested that death education incorporates cultural education, suicide/violence prevention and coping strategies (Wass, 2004). These may be especially relevant in the context of New Zealand considering its unique cultural view of death and high youth suicide rate (New Zealand Health Information Service, 2006). New Zealand primary caregivers’ perspectives on how death should be taught are still not known, though this may be similar to those expressed by parents in other English-speaking countries. Irish parents and teachers in one study strongly supported the view that before children encounter death, death should be discussed with them (Barry & Mcgovern, 2000) despite the teachers’ and parents’ reported discomfort with talking to children about death. Knowing that most children
understand that death is universal may ease parents’ discomfort. Children who survive into adulthood will not be sheltered from death forever.

The subcomponent of death on which caregivers most commonly misjudged their children’s scores was that of causation. If children know the causes of death (the heart stops beating and lungs cease breathing) and their caregivers do not believe they know this, perhaps caregivers are less likely to converse about the ways that people die. Conversely, if children do not know the causes of death and their caregivers believe they already understand them; their children may be attributing deaths to false causes that stress them. Children of this age often do not understand cause-and-effect relationships and may be egocentric (Piaget, 1954). For example, if a child ran out in the street on the day that their father crashed his car, she may believe that her action caused the crash. This research implies that primary caregivers may not need to worry about explaining the intricacies of the dying process because most children already understand the basics. This research should be applied with caution, however, as primary caregivers who participated and allowed their children to take part are also the most likely to be open to conversations about death simply due to the voluntary nature of the research. Considering that children of this age have been shown to decrease their fear of death once they conceptualise it as a biological concept (Slaughter & Griffiths, 2007), caregivers may be able to tackle deeper conversations about death more easily than they believe.

The majority of primary caregivers who spoke about avoiding talking with young people about prognoses eventually spoke to them. However, it is not clear if their reasons for delaying the process are justified, considering that they all related to protecting their children. Perhaps primary caregivers believe that their children’s emotions, perceptions and relationships are most vulnerable earlier in the process of receiving prognostic information.
Perceptions of Life and Death in Paediatric Palliative Care

The delays may be caused by primary caregivers being unprepared to discuss the prognosis. They may not have accepted the prognosis themselves. One caregiver stated:

The first thing parents have got to do is acknowledge where they’re at. If you can’t acknowledge what you’re up against, the reality of the situation, I don’t believe you can give your children the support they need... It doesn’t mean you accept it... but you have to acknowledge that you may be in a no-win situation. And once you do that, then you can get the resources to support you.

The value of more specific research into primary caregiver’s acceptance of terminal diagnoses may be worth the effort. Primary caregivers may, however, need to feel ready to accept their child’s death before they can begin thinking about how the information will affect their children. As mentioned previously, this “no-win situation” may be less painful when caregivers are able to help each other in other ways.

Family interaction is a priority of most family members involved in PPC in New Zealand. The interviewed siblings of PPC patients often desire to be involved in communication about and interaction with patients. In order to support young people’s cognitive and active coping styles, caregivers may involve them in the care of their siblings and/or communication about prognosis. As most of the participants across the studies referred to increased knowledge about the young person’s illness as contributing to family cohesiveness, increased communication should be considered. Of course, when deciding whether or not to talk about their child’s impending death, caregivers may take an individualised approach.

Many young people felt that others judged them prematurely because they did not know what it was like have an illness or disability. As it is commonly proposed that young people strive to “fit in” with their peers, normalising the situation of PPC may help young people.
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Providing information about PPC illnesses to the general public is one possible solution to normalising their illnesses and disabilities. This could be done through the education system, extracurricular activities or other means. Involving young people in advocating for causes is one means through which this concern may be addressed, considering that involvement in helping behaviour was generally seen as a positive activity.

Caregivers’ willingness to share information and openly express feelings about the family member who died may affect their children’s ability to cope. In bereaved families, more open communication between surviving caregivers and children (after the loss of a parent) correlated with lower levels of symptoms of depression and anxiety (Raveis, Siegel, & Karus, 1999).

Programmes aimed at helping children cope with change may allow children to express their feelings and facilitate positive changes. One study found almost 90% of parents noticing positive changes in their children following their participation in a focus group-style grief programme called “Seasons” (Tomoana, 2010). Seasons, allows children to “tell their story and be heard and supported in an environment which fosters trust” with other children in similar situations, reducing feelings of isolation (p. 33). Not only do these programmes help children cope with feelings and changes, they also support parents by taking some of the burden of responsibility (Rolls & Payne, 2007). This external support may be critical at a time when caregivers are grieving themselves. The external position of such programmes may also be advantageous in allowing children some control over what they wish to share with others (Tomoana, 2010). They may choose to share things with the group which they would not express within their families, perhaps for fear of making their family member upset (Rolls & Payne, 2007).
Perceptions of Life and Death in Paediatric Palliative Care

With the knowledge gained from this research, talking about death with children is not something to be feared. While direct conversations with young people may not be the best approach for everyone, they are worthy of consideration by primary caregivers, education providers and HCPs. Both ill and healthy children are affected by death within and external to their families. The more time individuals are given to prepare for death, the more opportunity they may have to deal with it in their own ways.
8.5. The Last Few Words

In summary, healthy children may have a slightly different awareness of death than their primary caregivers think. If this is the case (and if we can go so far as to equate healthy five to seven-year-olds to older children in families receiving PPC), then caregivers’ reasons for talking with their children about death or avoiding the topic may be based on a different set of information than the truth.

It is clear that primary caregivers want to prepare and protect their children and their conversations with children reflect this. It is also apparent that some young people want to prepare and protect the patient and other members of their families as well.

Young people may be concerned about the special treatment of patients, spending time with their families, experiencing judgment, and the impending death or that of their sibling. Many of them may want to be involved in their lives and care.

An individualised approach to caring for families of PPC patients is still, of course, the best one, but if we can gain some insight from hearing parts of the stories of a few brave families in New Zealand, then sharing their words has been worthwhile.
Appendices

Publications and Presentations


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Gaab, E. (March, 2010). To Talk or Not to Talk: Children’s perceptions of death within the context of Paediatric Palliative Care. *Quality of Life* Conference presentation. Auckland University of Technology.

Gaab, E. (February, 2010). To Talk or Not to Talk: Children’s perceptions of death within the context of Paediatric Palliative Care *Australasian Society for Behavioural Health and Medicine* Conference presentation. Brisbane, Australia.

**Research Forms and Graphs**
Focus on Whānau, siblings and patients

Many studies indicate that supporting families of children with life-limiting illnesses is essential. In order to help us provide the best support with decision-making for these children and families, we would like to hear about their experiences. If you help care for or have helped care for a child receiving palliative care and would like to know more about this project or share your thoughts and experiences, please let us know so we can give you more information.

Please contact Erin Gaab at the University of Auckland by email at e.gaab@auckland.ac.nz or by phone at 09 373 7599 extension 87818.

Project Plan:

Task 1: Explore themes arising from a family/whānau focus group.

Interpret the discussions between whānau and caregivers who have a child with a life-limiting illness or have lost a child to illness to build a context for other studies.

Task 2: Give patients and siblings a voice.

Examine the thoughts of paediatric palliative care patients and siblings in a hospital setting through the use of writing and audio recordings.

Task 3: Compare young children's perceptions of death to the understanding their caregivers believe the children hold.

Compare healthy children's death understandings to those predicted by caregivers.

Task 4: Analyse the views which siblings of paediatric palliative care patients hold.

Interview siblings to obtain their opinions of the roles they play in the care of their siblings and the support they receive during the process.

PLEASE CONTACT ERIN TO LEARN MORE
ABOUT HER STUDIES:

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THE UNIVERSITY
OF AUCKLAND
NEW ZEALAND
Te Whare Wānanga o Tamaki Makaurau

Advertisement Version 2, 23/10/2009
Approved by Northern X Regional Ethics Committee
Appendix 2

Hyundai Wheels of Courage
WIN THIS CAR!
AND SUPPORT THE CHILD CANCER FOUNDATION

Purchase supporters’ bead bracelets for $5 each and go in the draw to win a Hyundai Santa Fe! To purchase visit Farmers or www.childcancer.org.nz

Help us reach our goal of 75,000 bead bracelets, one for each of the 75,000 procedures children with cancer receive each year on their journey.

SUPPORTED BY:


Paediatric Palliative Care Research:

Studies have indicated that supporting families of children with life-limiting illnesses is essential.

In order to help us provide the best support with decision-making for these children and families, we would like to hear about their experiences. If you help care for, or have helped care for a child receiving palliative care and would like to know more about this project or share your thoughts and experiences, please let us know so we can give you more information.

OBJECTIVES:

- This study seeks to help whānau and caregivers by assessing children’s perceptions of death in the Paediatric Palliative Care (PPC) context.
- It explores children’s conceptualisations of their illnesses and understandings of death.
- It addresses the role communication plays between parents and children at the end of a child’s life.
- What do children understand about their own mortality and the mortality of their brothers and sisters?
- Is verbal communication the method through which parents and children cope together?
- What role do culture and religion play?

WHO CAN PARTICIPATE IN THIS RESEARCH?

- Parents
- Siblings aged 10-20
- Grandparents
- Cousins (adults)
- Aunts & Uncles
- Patients aged 10-20

PLEASE CONTACT Erin Gaab at the University of Auckland by email at e.gaab@auckland.ac.nz or by phone at 09 373 7599 extension 87818
Appendix 3
Children’s Understanding of the Human Lifecycle Interview

(Reilly et al., 1983; Slaughter & Griffiths, 2007, Table 1)

Child’s Name: ___________________________________  Child’s Gender: F M
Ethnicity (optional): _______________________________  Child’s Age: 5 6 7

Primary Caregivers: Please answer the following questions as you think your child will answer them. Please do not discuss these questions with your child before he or she is interviewed.

Subcomponent  Interview question

Inevitability  1. ‘Tell me some things that die’ (if people are not named ask, ‘Do people die?’)

2. ‘Do all [entities mentioned in answer to question 1] die’?

Applicability  3. ‘Tell me some things that don’t die.’

Irreversibility  4. ‘Can a dead person ever become a living person?’

5. ‘If a person dies and they haven’t been buried in their grave for very long can they become a live person again?’

Cessation  6. ‘When a person is dead . . . (a) Do they need food?

(b) Do they need to go to the toilet?

(c) Do they need air?

(d) Can they move around?

(e) Do they have dreams?

(f) Do they need water?’

Causation  7. Can you tell me something that might happen that would make someone die?

When ________ happens, why does that person really die?

Personal Mortality  8. Do you think that someday you will die?

Thank you for your participation!

Appendix 4

Children’s Understanding of the Human Lifecycle Interview Scoring Guide

Inevitability: 1. ‘Tell me some things that die’ (if people are not named ask, ‘Do people die?’)

2. ‘Do all [entities mentioned in answer to question 1] die’?

0 points – People were not mentioned as dying, and when given question 2, people were held not to die

1 point – People were not mentioned as dying, and when given question 2, people were held not to die. Or, people were mentioned as dying but when given the forced choice, people were held not to die

2 points – People were mentioned as dying and all people were held to die

Applicability: 3. ‘Tell me some things that don’t die.’

0 points – Only living things were mentioned (e.g. ‘kids, dogs, fish’)

1 point – A mixture of living and nonliving things were mentioned (e.g., ‘books, bricks, trees, old people’)

2 points – Only nonliving things were mentioned (e.g. ‘houses, fences, bricks’)

Irreversibility: 4. ‘Can a dead person ever become a living person?’

5. ‘If a person dies and they haven’t been dead for very long can they become a live person again?’

0 points – Incorrect on both questions 4 and 5 (answers yes to both questions)

1 point – One of the questions 4 or 5 correctly answered (answers ‘no’ to one question)

2 points – Both questions 4 and 5 answered correctly (answers ‘no’ to both questions)

Cessation: 6. ‘When a person is dead . . .

(a) Do they need food? (b) Do they need to go to the toilet?

(c) Do they need air? (d) Can they move around?

(e) Do they have dreams? (f) Do they need water?

0 point – Two or fewer of items (a)–(f) correctly answered

1 point – More than 2, but fewer than 6 of items (a)–(f) correctly answered
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2 points – All items (a)–(f) correctly answered

Causation: 7. Can you tell me something that might happen that would make someone die?

When _______ happens, why does that person really die?

0 points – External cause of death given (e.g. ‘knife because they are bad’)

1 point – Reference to the body was given but did not refer to a biological cause (e.g. ‘knife, because it cuts into your body’)

2 points – Fully explicit biological causal (e.g. ‘knife because it cuts your body and all your blood comes out so you die’).

Personal Mortality: 8. Do you think that someday you will die?

0 points – Answers ‘no’

1 point – Answers possibly (e.g., ‘maybe,’ ‘only when I am old’)

2 points – Answers yes
Appendix 5

OPTIONAL: Anonymous Questionnaire

Reasons for **declining to participate** in the study of...

*Primary Caregivers’ Understanding of Children’s Understanding of Death; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life:*

Which ethnicity/ethnicities do you identify with? ________________________________

I chose not to take part or let my child take part because of...

*Please check all that apply:*  
*Please state reason (OPTIONAL):*

- Personal reasons __________________________________________________________
- Cultural reasons __________________________________________________________
- Religious reasons _________________________________________________________
- Other reasons ____________________________________________________________

*Thank you!*
Appendix 6

Participant Information Sheet (Principal)

Title:  Primary Caregivers’ Understanding of Children’s Understanding of the Human Lifecycle; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life

Researcher:  Erin Mary Gaab, PhD Candidate

Your school is invited to take part in a study which may help children receiving paediatric palliative (end of life) care (PPC). This research seeks to understand children’s understanding of death as a biological concept and their primary caregivers’ perceptions of what they understand. It seeks to help parents and guardians decide whether or not to talk about death with their children at the end of their lives. You have been selected because your organisation contains a sample of children which reflects potential PPC patients.

I would like to send letters through your school to guardians. I would also like access to your facilities and to children of consenting guardians. The guardians will be informed that you cannot give permission on the behalf of the child to participate and that he or she may withdraw from the study. I would like to seek assurance that participation, or non-participation, will not affect the treatment of the children in your school.

Rationale for the Research

One important question which arises within families receiving paediatric palliative care (PPC) is whether or not parents should discuss death with their children. The depth of information about the child’s illness trajectory which parents share with their children may be influenced by the knowledge the parent believes the child already holds about it (Kreicbergs, 2004). Since PPC is recognised in most countries as a family-centred approach to treating the child (Armstrong-Dailey, 1993), this issue is extremely relevant and important. Parental grief in reaction to the death of a child is more intense than grief experienced in response to other losses such as the death of a parent or spouse (Middleton, Raphael, Burnett, & Martinek, 1998) and the communication between parents and children is critical at the end of life.

There may be a large discrepancy between the knowledge children hold about their terminal illnesses and the knowledge which their parents believe they hold. This discrepancy may be the cause of parents’ decisions not to disclose information to their children. In a survey of bereaved children who were given the opportunity to ask questions to a doctor, the largest category of questions identified was 52% relating to
the cause of death (F. Thompson & Payne, 2000). Though the study did not specifically focus on siblings of children lost to terminal illness, it suggests that children may be frequently left out of conversations which could prepare them. Significant research supports the practice of including children facing the end of life in decisions about their care (Faulkner, 1997). Likewise, the inclusion of siblings in conversations about the care of a child at the end of his or her life correlate with a more positive outlook following the death of a sibling from cancer (Ida M. Martinson & Campos, 1991).

However, many people still believe that dying children under 10 years of age are not aware that they are dying and that dying children’s questions should not be answered (Himelstein et al., 2004). Himelstein et al. contrasts the myths some caregivers hold that sheltering children from the knowledge of impending death will protect their children’s innocence from pain and suffering with the reality that children will inevitably be exposed to death in play, the media or through personal experiences (2004).

A study from the Division of Nursing at the University of Auckland noted the serious problem of the lack of research, specifically New Zealand research, in the development of children’s palliative care services (Horsburgh, 2000).

A recent study of bereaved parents (Kreicbergs, 2004) obtained information from 429 of the 561 eligible parents in Sweden whose children had died of cancer between 1992 and 1997. They asked the parents “whether or not they had talked about death with their child” and whether or not they regretted having that conversation. Of the 147 parents who talked about death with their child, none of them regretted it. However, of the 258 parents who talked with their children about death, 69 parents (27 percent) regretted not having that conversation. The researchers concluded that parents who believed their children were aware of their impending deaths more often regretted not having talked about death with their children. Parents who did not sense the awareness of death in their child were less likely to regret not talking to them about it.

This study will be conducted in conjunction with other studies including whanau focus groups, an ethnographic study of paediatric palliative care patients and siblings, and interviews of PPC patients’ siblings.

**Procedure**

Should you choose to participate, individual teachers will be contacted in the same way that you were and informed of the study. After consent is obtained from all parties, the study consists of two parts: a questionnaire for guardians to complete at home and a short interview for children to complete during (recess or lunchtime) or after school time (5-15 minutes).

The “Children’s Understanding of the Human Lifecycle Interview” assesses the knowledge of five biological subcomponents of the death concept. The same interviews will be given to each participant’s primary caregiver, who will be asked to predict how they believe her or his child will answer by answering as if they are his or her own child. The results of the children’s and parents’ interviews will be compared as subsets within the group.

Each child will be given a letter of thanks and debriefing form to take home to their primary caregivers. The letter will include the principal investigator’s contact information,
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should any issues arise following the study. Participants will be informed that counsellors will be available on request to any families who may need them.

A second form will be included in a stamped envelope, asking non-participants why they are choosing not to take part. This form will also be optional, but seeks to note the limitations of the study.

**Participation in the Research**

Your choice to take part in this research is completely voluntary. Potential participants may withdraw from the research at any time. Once collected, their data will be stored in a secured cabinet at the University of Auckland to which only the researcher and her supervisor will have access. Participants will be able to withdraw their data from the research up to two months after it is collected. The papers will be kept for six years before they are shredded.

Interviews will be recorded in writing only with the consent of each child. The identity of non-participants cannot be guaranteed because children will see other children being pulled out of the other children’s settings during their break times. They may notice one child not getting the same attention from the researcher.

The information that guardians and their children contribute to this study may be disseminated via journal articles at the end of this project. Information will not be linked to individual participants’ names or identifying factors in publications to ensure their confidentiality and anonymity. A summary of the combined results of all participants will be sent to you should you choose to participate as well as to primary caregivers of participants who request it and give their contact information upon the completion of the study.

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Supervisor</th>
<th>Head of Department</th>
</tr>
</thead>
</table>
| Erin Gaab, Health Psychology  
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For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 83711

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
Appendix 7

Consent Form (Principal)

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Title: Primary Caregivers’ Understanding of Children’s Understanding of the Human Lifecycle; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life

Researcher: Erin Mary Gaab, PhD Candidate

I have read the Participant Information Sheet and have understood the nature of the research and why my school has been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I agree to send forms out to the guardians of children at my school.
- Children will not participate unless their guardians do first.
- The participation of guardians and children within my school in this research is entirely voluntary and non-participation will have no negative effects.
- I agree to allow guardians to take part in this research which may take them 5-15 minutes.
- I understand that students’ and parents’ names will not be associated with my data in publications. All participants’ information will remain strictly confidential and anonymous.
- I understand that guardians and children will be able to withdraw any information once provided for up to two months following data collection and they may decide not to answer a question.
- I understand that children will be removed from school break time to participate for 5-15 minutes.
- I understand that children will be made to feel comfortable and have the purpose of the study explained to them. They will then be asked to sign their names on the consent form before answering the questions listed on the interview sheet. They can spend as much time answering as they would like.
- I understand that data will be kept in a secure, confidential location for 6 years post-publication.
- I wish / do not wish to receive the summary of the findings. (Please circle one)

Signed: ___________________________________________

Name (Please print clearly): _____________________________

Date: _____________________________________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
Appendix 8

Participant Information Sheet (Teacher)

Title: Primary Caregivers’ Understanding of Children’s Understanding of the Human Lifecycle; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life

Researcher: Erin Mary Gaab, PhD Candidate

Children from your class are invited to take part in a study which may help children receiving paediatric palliative (end of life) care (PPC). This research seeks to understand children’s understanding of death as a biological concept and their primary caregivers’ perceptions of what they understand. It seeks to help parents and guardians decide whether or not to talk about death with their children at the end of their lives. You have been selected because your organisation contains a sample of children which reflects potential PPC patients.

I would like to access to your facilities and the children of consenting guardians. The guardians will be informed that you cannot give permission on the behalf of the child to participate and that he or she may withdraw from the study. I would like to seek assurance that participation, or non-participation, will not affect the treatment of the children in your school.

Rationale for the Research

One important question which arises within families receiving paediatric palliative care (PPC) is whether or not parents should discuss death with their children. The depth of information about the child’s illness trajectory which parents share with their children may be influenced by the knowledge the parent believes the child already holds about it (Kreicbergs, 2004). Since PPC is recognised in most countries as a family-centred approach to treating the child (Armstrong-Dailey, 1993), this issue is extremely relevant and important. Parental grief in reaction to the death of a child is more intense than grief experienced in response to other losses such as the death of a parent or spouse (Middleton et al., 1998) and the communication between parents and children is critical at the end of life.

There may be a large discrepancy between the knowledge children hold about their terminal illnesses and the knowledge which their parents believe they hold. This discrepancy may be the cause of parents’ decisions not to disclose information to their children. In a survey of bereaved children who were given the opportunity to ask questions to a doctor, the largest category of questions identified was 52% relating to...
Perceptions of Life and Death in Paediatric Palliative Care

the cause of death (F. Thompson & Payne, 2000). Though the study did not specifically focus on siblings of children lost to terminal illness, it suggests that children may be frequently left out of conversations which could prepare them. Significant research supports the practice of including children facing the end of life in decisions about their care (Faulkner, 1997). Likewise, the inclusion of siblings in conversations about the care of a child at the end of his or her life correlate with a more positive outlook following the death of a sibling from cancer (Ida M. Martinson & Campos, 1991).

However, many people still believe that dying children under 10 years of age are not aware that they are dying and that dying children’s questions should not be answered (Himelstein et al., 2004). Himelstein et al. contrasts the myths some caregivers hold that sheltering children from the knowledge of impending death will protect their children’s innocence from pain and suffering with the reality that children will inevitably be exposed to death in play, the media or through personal experiences (2004).

A study from the Division of Nursing at the University of Auckland noted the serious problem of the lack of research, specifically New Zealand research, in the development of children’s palliative care services (Horsburgh, 2000).

A recent study of bereaved parents (Kreicbergs, 2004) obtained information from 429 of the 561 eligible parents in Sweden whose children had died of cancer between 1992 and 1997. They asked the parents “whether or not they had talked about death with their child” and whether or not they regretted having that conversation. Of the 147 parents who talked about death with their child, none of them regretted it. However, of the 258 parents who talked with their children about death, 69 parents (27 percent) regretted not having that conversation. The researchers concluded that parents who believed their children were aware of their impending deaths more often regretted not having talked about death with their children. Parents who did not sense the awareness of death in their child were less likely to regret not talking to them about it.

This study will be conducted in conjunction with other studies including whanau focus groups, an ethnographic study of paediatric palliative care patients and siblings, and interviews of PPC patients’ siblings.

Procedure

This study consists of two parts: a questionnaire for guardians to complete at home and a short interview for children to complete during (recess or lunchtime) or after school time (5-15 minutes).

The “Children’s Understanding of the Human Lifecycle Interview” assesses the knowledge of five biological subcomponents of the death concept. The same interviews will be given to each participant’s primary caregiver, who will be asked to predict how they believe her or his child will answer by answering as if they are his or her own child. The results of the children’s and parents’ interviews will be compared as subsets within the group.

Each child will be given a letter of thanks and debriefing form to take home to their primary caregivers. The letter will include the principal investigator’s contact information, should any issues arise following the study. Participants will be informed that counsellors will be available on request to any families who may need them.
Participation in the Research

Your choice to take part in this research is completely voluntary. Should you choose not to take part, you and your class will not be treated any differently and non-participation will have no negative effects. Potential participants may withdraw from the research at any time. Once collected, their data will be stored in a secured cabinet at the University of Auckland to which only the researcher and her supervisor will have access. They will be able to withdraw their data from the research up to two months after it is collected. The papers will be kept for six years before they are shredded.

Interviews will be recorded in writing only with the consent of each child. The identity of non-participants cannot be guaranteed because children will see other children being pulled out of the other children’s settings during their break times. They may notice one child not getting the same attention from the researcher.

The information that guardians and their children contribute to this study may be disseminated via journal articles at the end of this project. Information will not be linked to individual participants’ names or identifying factors in publications to ensure their confidentiality and anonymity. A summary of the combined results of all participants will be sent to you should you choose to participate as well as to primary caregivers of participants who request it and give their contact information upon the completion of the study.

Principal Investigator | Supervisor | Head of Department
--- | --- | ---
Erin Gaab, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 64 9 373 7599 ext. 87818 Email: e.gaab@auckland.ac.nz | Glynn Owens, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 64 9 373 7599 ext. 86221 Email: g.owens@auckland.ac.nz | Linda Cameron, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 64 9 373 7599 ext. 86869 Email: l.cameron@auckland.ac.nz

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 83711

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
Appendix 9

Consent Form (Teacher)

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Title: Primary Caregivers’ Understanding of Children’s Understanding of the Human Lifecycle; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life

Researcher: Erin Mary Gaab, PhD Candidate

I have read the Participant Information Sheet and have understood the nature of the research and why my school has been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I agree to allow children with consenting guardians to be removed from my class to participate.
- Children will not participate unless their guardian does first.
- The participation of guardians and children within my school in this research is entirely voluntary and non-participation will have no negative effects.
- I agree to allow guardians to take part in this research which may take them 5-15 minutes.
- I understand that students’ and parents’ names will not be associated with my data in publications. All participants’ information will remain strictly confidential and anonymous.
- I understand that guardians and children will be able to withdraw any information once provided for up to two months following data collection and they may decide not to answer a question.
- I understand that children will be removed from school break time to participate for 5-15 minutes.
- I understand that children will be made to feel comfortable and have the purpose of the study explained to them. They will then be asked to sign their names on the consent form before answering the questions listed on the interview sheet. They can spend as much time answering as they would like.
- I understand that data will be kept in a secure, confidential location for 6 years post-publication.
- I wish / do not wish to receive the summary of the findings. (Please circle one)

Signed: ______________________________________
Name (Please print clearly): ______________________________________
Date: ______________________________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
Appendix 10

Participant Information Sheet (Parent)

Title: How do Children Understand of the Human Lifecycle? Informing Parents with Terminally Ill Children

Researcher: Erin Mary Gaab, PhD Candidate

You and your child are invited to take part in a study which may help families of children who are not expected to live into adulthood. This research aims to compare what parents think their children know about the lifecycles to what children themselves report. It seeks to help guardians decide whether or not to talk about life and death with their terminally ill children. You have been selected because you live in Auckland with a young child. The principal of the school your child attends was informed of the study and chose to invite you to take part.

Why conduct this research?

One important question families with very sick children ask is whether or not they should discuss death with their children. What parents think their children already know affects what they talk about with their children. The communication between parents and children is critical at the end of life.

There may be a large difference between the knowledge children hold about their terminal illnesses and the knowledge which their parents believe they hold. This difference may be why some parents choose not to talk about death with their children. In a survey of bereaved children who were given the opportunity to ask questions to a doctor, 52% of them related to the cause of death. Children may be left out of conversations which could prepare them. Research advises including very sick children in decisions about their care. However, many people believe that dying children under 10 years of age are not aware that they are dying and that their questions should not be answered.

There is very little research, specifically New Zealand research, in the development of children’s palliative care services. This study will be conducted in addition to other studies of PPC patients, siblings, and whanau.

How does the study work?

The study consist of two parts: a questionnaire for you to complete at home which will take 5-15 minutes and a short interview for your child to complete at school time which will take 5-15 minutes.
The “Children’s Understanding of the Human Lifecycle Interview” (CUHLI) assesses children’s knowledge about life and death. First, you will be asked to predict how you believe your child will answer the questions by answering as if you are your own child. Next, your child will be interviewed. The results of your and your child’s interviews will be compared. Please do not discuss the questions on the CUHLI with your child between now and when your child is interviewed. This is a study of the connection between what children know and what their caregivers think they know.

Your child will be given a letter of thanks and debriefing form to take home to you after he/she is interviewed. The letter will include my contact information, should any issues arise following the study. Counsellors will be available on request.

If you decide not to take part, I would like to note why. There is an optional form enclosed that seeks to note the limitations of the study.

Will you take part?

Your choice to take part in this research is completely voluntary. Should you choose not to take part, you and your child will not be treated any differently from anyone else in your school.

You have the right to withdraw from the research at any time. Once collected, your data will be stored in a secured cabinet at the University of Auckland to which only the researcher will have access. You may withdraw your data up to two months after it is collected. The papers will be kept for six years before they are shredded.

The identity of non-participants cannot be guaranteed because children will see other children being pulled out of the other children’s settings during their break times. They may notice one child not getting the same attention from the researcher.

The information that you and your child contribute to this study may be shared in journal articles at the end of this project. Information will not be linked to your or your child’s name or anything that could be used to identify you in publications. A summary of the combined results of all participants will be sent to you should you choose to participate. In order to receive the results, you must request them and give your contact information to the researcher upon the completion of the study.

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Supervisor</th>
<th>Head of Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erin Gaab, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 64 9 373 7599 ext. 87818 Email: <a href="mailto:e.gaab@auckland.ac.nz">e.gaab@auckland.ac.nz</a></td>
<td>Glynn Owens, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 64 9 373 7599 ext. 86221 Email: <a href="mailto:g.owens@auckland.ac.nz">g.owens@auckland.ac.nz</a></td>
<td>Linda Cameron, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 64 9 373 7599 ext. 86869 Email: <a href="mailto:l.cameron@auckland.ac.nz">l.cameron@auckland.ac.nz</a></td>
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For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 83711.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
Appendix 11

Consent Form (Parent)

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Title: Primary Caregivers’ Understanding of Children’s Understanding of the Human Lifecycle; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life

Researcher: Erin Mary Gaab, PhD Candidate

I have read the Participant Information Sheet and have understood the nature of the research and why my school has been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- My child will not participate unless I do first.
- My child’s and my participation is entirely voluntary. The researcher has the assurance of the principal that participation or non-participation will not affect how children are treated.
- I agree to take part in this research which may take me 5-15 minutes.
- I agree not to discuss these questions with my child before he or she is interviewed.
- I understand that and my child’s and my names will not be associated with my data in publications. Our information will remain strictly confidential and anonymous.
- I understand that I may withdraw any information once provided for up to two months following data collection and that I or my child may decide not to answer a question.
- I understand that children will be removed from school break time to participate for 5-15 minutes.
- I understand that children will be made to feel comfortable and have the purpose of the study explained to them. They will then be asked to sign their names on the consent form before answering the questions listed on the interview sheet. They can spend as much time answering as they would like.
- I understand that data will be kept in a secure, confidential location for 6 years post-publication.
- I wish / do not wish to receive the summary of the findings. (Please circle one)

Signed: __________________________________________

Name (Please print clearly): _________________________________________

Child’s Name: _________________________________________

Date: _________________________________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
Appendix 12

March 2010

Kia ora Primary Caregiver,

You are invited to help families with children who are terminally ill and their families in deciding what to discuss with their children. Please read the enclosed information, fill out the forms (if you are willing), and post back to researcher Erin in the freepost envelope.

This study has been approved by authorities at Balmoral School and the University of Auckland.

Thank you very much,
Erin Gaab
PhD candidate

May, 2010

Kia ora Parent/ Caregiver,

You are invited to help families with children who are terminally ill and their families in deciding what to discuss with their children. Please read the enclosed information, fill out the forms (if you are willing), and post back to researcher Erin in the freepost envelope.

This study has been approved by authorities at Willowbank School and the University of Auckland.

Thank you very much,
Erin Gaab
PhD candidate
8 March 2010

Dear Parents

Last week, I had the opportunity to meet a wonderful young lady called Erin Gaab, who is a PhD student at the University of Auckland.

As part of her learning, Erin is doing a study which may help children receiving end of life care. (Paediatric Palliative Care). In this study, she is looking at developing understandings for parents and children in a time when life for them can be very difficult.

I am sure that this research will help parents and children who face this prospect at some time.

Erin’s research has the full approval of the University of Auckland’s Human Participants Ethics Committee.

Erin has asked me if she could contact parents from our school, asking them to take part in her study. She will send you an information pack which outlines the requirements for this.

Erin is a woman of integrity. I enjoyed meeting with her and fully support her study. You may like to consider taking part in this too.

Yours sincerely

Principal’s Signature

PRINCIPAL
Appendix 13

Assent Form

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Title: Primary Caregivers' Understanding of Children's Understanding of the Human Lifecycle; How Beliefs about Children's understanding of death as a biological event affects Parents' Communication with Children about the End of Life

Researcher: Erin Mary Gaab, PhD Candidate

Erin explained this research project to me. I had time to ask all the questions I wanted to ask and got them answered.

I can say I don’t want to take part and nothing bad will happen because of it.
I don’t have to participate— I am taking part because I want to.
I will leave school time to take part in this study for 5-15 minutes.
I can stop answering questions at any time.
I can take as much time as I like to answer the questions.
I can tell my guardian that I don’t want to participate in the project anymore so that Erin no longer keeps my opinions until two months from now.
Nobody will know which answers I gave because Erin will put them with other children's answers in a big group.
Six years after Erin is done writing about this, my answers to the questions will be thrown away.
I agree / do not agree to be interviewed

Signed: __________________________________________

Name (Please print clearly): __________________________________________

Date: __________________________________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15/07/09 for (3) years, Reference Number 2009/297
DEBRIEFING FORM
Child and Primary Caregiver

Project title: Primary Caregivers’ Understanding of Children’s Understanding of the Human Lifecycle; How Beliefs about Children’s understanding of death as a biological event affects Parents’ Communication with Children about the End of Life

Name of Researcher: Erin Mary Gaab, PhD Candidate

Thank you so much for participating in this research!

Your answers will help me to learn what children know about the human lifecycle and their family’s thoughts about it.

If you decide later that you don’t want me to use the answers you gave me, you can tell me until two months from now.

If any issues arise following this study, please contact the principal investigator. If she cannot help you, she will refer you to a person or service who can.

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Supervisor</th>
<th>Head of Department</th>
</tr>
</thead>
<tbody>
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<td>Glynn Owens, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 09 373 7599 ext. 86221 Email: <a href="mailto:g.owens@auckland.ac.nz">g.owens@auckland.ac.nz</a></td>
<td>Linda Cameron, Health Psychology Tamaki Campus The University of Auckland Private Bag 92019 Auckland, New Zealand Tel.: 09 373 7599 ext. 86869 Email: <a href="mailto:l.cameron@auckland.ac.nz">l.cameron@auckland.ac.nz</a></td>
</tr>
</tbody>
</table>

If you are interested in receiving a summary of the results once they are compiled, please send your contact information to the principal investigator.

Thank you very much for your time and information.
Appendix 15

Mean = 0.96
Std. Dev. = 1.51
N = 141

Difference (Child - Primary Caregiver score on CUHLI)
Appendix 16

Early Findings from first two Auckland primary schools:

Vertical (Y) Axis represents Predicted CUHLI Score
Horizontal (X) Axis represents each child/ parent pair
32 parent/child pairs have been surveyed and interviewed.
Appendix 17

CUHLI Scoring Guide

Inevitability: 0 points – People were not mentioned as dying, and when given question 2, people were held not to die

1 point – People were not mentioned as dying, and when given question 2, people were held not to die. Or, people were mentioned as dying but when given the forced choice, people were held not to die

2 points – People were mentioned as dying and all people were held to die

Applicability: 0 points – Only living things were mentioned (e.g. ‘kids, dogs, fish’)

1 point – A mixture of living and nonliving things were mentioned (e.g., ‘books, bricks, trees, old people’)

2 points – Only nonliving things were mentioned (e.g. ‘houses, fences, bricks’)

Irreversibility: 0 points – Incorrect on both questions 4 and 5 (answers yes to both questions)

1 point – One of the questions 4 or 5 correctly answered (answers ‘no’ to one question)

2 points – Both questions 4 and 5 answered correctly (answers ‘no’ to both questions)

Cessation: 0 point – Two or fewer of items (a)–(f) correctly answered

1 point – More than 2, but fewer than 6 of items (a)–(f) correctly answered

2 points – All items (a)–(f) correctly answered

Causation: 0 points – External cause of death given (e.g. ‘knife because they are bad’)

1 point – Reference to the body was given but did not refer to a biological cause (e.g. ‘knife, because it cuts into your body’)

2 points – Fully explicit biological causal (e.g. ‘knife because it cuts your body and all your blood comes out so you die’).

Personal Mortality: 0 points – Answers ‘no’

1 point – Answers possibly (e.g., ‘maybe,’ ‘only when I am old’)

2 points – Answers yes
Perceptions of Life and Death in Paediatric Palliative Care

Appendix 18

Average Differences (Child - Caregiver Score):

- Inevitability
- Applicability
- Irreversibility
- Cessation
- Causation
- Personal Mortality
Appendix 19

Children’s understanding of the death subcomponents

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<th>Dimension</th>
<th>Percentage of children scoring:</th>
<th>Percentage of caregivers scoring:</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Inevitability</td>
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<tr>
<td>Applicability</td>
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<td>18</td>
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<tr>
<td>Irreversibility</td>
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<td>11</td>
</tr>
<tr>
<td>Cessation</td>
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<td>28</td>
</tr>
<tr>
<td>Causation</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>Personal Mortality</td>
<td>9</td>
<td>2</td>
</tr>
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</table>

*Individual differences (child - caregiver score)*

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Caregivers who accurately predicted children</th>
<th>Caregivers who underestimated children</th>
<th>Caregivers who overestimated children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inevitability</td>
<td>105</td>
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<td>15</td>
</tr>
<tr>
<td>Applicability</td>
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</tr>
<tr>
<td>Irreversibility</td>
<td>90</td>
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<td>18</td>
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<td>Causation</td>
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<tr>
<td>Personal Mortality</td>
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<td>82</td>
<td>24</td>
</tr>
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</table>
Appendix 20

Caregivers’ reasons for declining to participate in Study One

Reasons for Declining to Participate
(42 DTP forms)
Appendix 21

Questionnaire

**Name of Study:** Exploring the Voices of Parents and Whanau, Increasing our understanding of families’ experiences by listening to families involved in paediatric palliative care

Thank you so much for taking time out of your busy schedule to help me with my research by answering the PPC focus group questions.

My name is Erin and I am a health psychology PhD student at the University of Auckland. I volunteered at a children’s hospice in the United States for five years which led me to research in this field. I played with, read to and just sat with many paediatric palliative care (PPC) patients, siblings, cousins and friends during that time. I wrote my honours thesis entitled “Children’s End of Life Care” two years ago. There is not a lot of research that has been done of families receiving PPC, and an extremely small amount on families in New Zealand. Though I have not experienced what you have been through with your child, I have seen many families go through similar difficulties. I am conducting a few focus groups as a part of my doctoral studies at the University of Auckland.

My supervisors and advisors include Rod MacLeod, Glynn Owens and Andrew Thompson*. Rod is a clinician at Hibiscus Coast Hospice and professor of Population Health at the University of Auckland. Glynn is a professor of Health Psychology at the University of Auckland and specialist in end-of-life care. He holds a diploma of clinical psychology along with other psychology degrees. Andrew is a social worker on the Consult Liaison Psychiatry team at Starship. He’s studied PICU meetings and used to work as a member of the Paediatric Palliative Care team as well.

This project aims to inform families and clinicians who work with children and their siblings at the end of life, specifically regarding the topic of whether or not to talk with that child about their illness and possible impending death. You are one of the real experts in this field. You have lived with or are living with children in these situations. You have likely struggled with issues of what to talk about and withhold from your child. You have made or are making the difficult decisions and facing the consequences of them.

I value your opinion more than anything right now. There is no right answer to any of the questions I am asking of you. Each family and each person within that family may feel differently about what “the right thing to do” is. PPC patients vary in many different ways including age, cognitive ability, exposure to medical treatment, and others. Whanaus differ drastically in terms of culture, religion, parenting style, and views of life and death.
After I type up the statements you have disclosed in this group, I will email or post them to you. You may then edit your own comments and send them back to me if you would like. Your names, the names of your children, and other things that might allow readers to identify you will be taken out of the scripts. If you allow me to use the age and illness of your child, I may use that to clarify the context, but not without your written permission.

You have read and signed participant information sheet and consent form. My contact information is on the information sheets if you need to contact me at a later time. If you experience any negative effects from this group, you may contact me and I will ensure that you are directed to someone who can help you, whether that is a bereavement counsellor, social worker or someone else. I have experienced supervisors at the University of Auckland who I may share your information with if necessary to connect you with the proper follow-up support.

We will aim to spend about 15 minutes exploring answers to each question. There are six focus questions and additional time to give last comments in conclusion. You do not need to answer any questions you do not want to answer and you may leave at any time without giving a reason.

Are there any questions about this before we begin?

Please state your name (to match names with voices for transcription)

1. In two or three minutes, could you please just outline for me the background/circumstances of your child’s illness?

2. Could you say a little about how you went about talking to your child about his or her illness?
   a. How did you decide what things to discuss?
   b. What was that process like? Who was involved?

3. How much do you think your child understood about how serious his/her illness was?

4. On reflection, how do you feel about your decision to talk or not talk with your child about his or her death?

5. How should a researcher approach parents, brothers, sisters (currently coping or bereaved) and patients when exploring this topic?

6. If you could give any advice to whanau / families of PPC patients regarding communicating about illness and/or death with their children, what would it be?

7. Is there anything else you would like to talk about or that you thought about while we were talking?

Thank you.
Perceptions of Life and Death in Paediatric Palliative Care

Appendix 22

Participant Information Sheet

Name of the study PPC Family/ Whānau Focus Groups

<table>
<thead>
<tr>
<th>Principal Investigator: Erin Gaab</th>
<th>Supervisor: Glynn Owens</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhD student</td>
<td>Professor of Psychology</td>
</tr>
<tr>
<td>Department of Psychology</td>
<td>Department of Psychology</td>
</tr>
<tr>
<td>Tamaki Campus</td>
<td>Tamaki Campus</td>
</tr>
<tr>
<td>University of Auckland</td>
<td>University of Auckland</td>
</tr>
<tr>
<td>Private Bag 92019</td>
<td>Private Bag 92019</td>
</tr>
<tr>
<td>Auckland, New Zealand</td>
<td>Auckland, New Zealand</td>
</tr>
<tr>
<td>+64 9 373 7599 ext. 87818</td>
<td>+64 9 373 7599 ext. 86845</td>
</tr>
</tbody>
</table>

You are invited to take part in a research study about your family’s / whānau’s perceptions of communication with children about illness, life and death. This project aims to explore the your voice to increase our understanding of the experiences of families involved in paediatric palliative care.

Please take your time to think about it and decide whether you wish to take part. Taking part is completely voluntary (your choice) and if you decided you do not wish to take part, it will not affect your continuing healthcare in any way.

Why are you being asked? / what it all about?

One important question which arises within families receiving paediatric palliative care (PPC) is whether or not parents should discuss death with their children. Since PPC is a family-centred approach to treating the child, this issue is extremely relevant and important. Parental grief in reaction to the death of a child is more intense than grief experienced in response to other losses and the communication between parents and children may be critical at the end of life.

There may be a large discrepancy between the knowledge children hold about their illnesses and the knowledge which their parents believe they hold. This discrepancy may be the cause of parents’ decisions not to disclose information to their children. In a survey of bereaved children who were given the opportunity to ask questions to a doctor, the largest category of questions identified was 52% relating to the cause of death. Children may be frequently excluded from conversations about their illnesses. Many people believe that dying children under 10 years of age are not aware that they are dying. Some caregivers believe that sheltering children from the knowledge of impending death will protect their children from pain and suffering despite the reality that children will be exposed to death in play, the media or through personal experiences.

A study from the Division of Nursing at the University of Auckland noted the serious problem of the lack of research, specifically New Zealand research, in the development of children’s palliative care services.

< PPC Family/ Whanau Focus Groups >
Participant Information Sheet Version 2, 23/10/09

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This study will be conducted in conjunction with other studies of paediatric palliative care patients and siblings and a comparison of healthy children’s and their primary caregivers’ perceptions of death.

- This group will take place next month or the following month and will last one and a half to two hours.
- You are invited to participate because you either have a child who is receiving paediatric palliative care or you lost a child to a terminal illness. Six to fifteen family/whānau members who fit these criteria will be participating in total, though the focus groups will be split into parents with children receiving PPC and those whose children have passed away. Only adults fluent in English language may participate.

What happens during the study?

- A focus group is an interactive, social research method. Focus groups are commonly used in marketing research to get people’s opinions of products or services. They are also used to raise unexpected issues for exploration and to get a variety of perspectives in a more natural setting than an interview.
- This focus group will take place at the Child Cancer Foundation Family Support Building or a location that you and other members of the groups find mutually more appropriate. It will last one and a half to two hours followed by a debriefing period in which dinner will be offered to you and your family. We will aim to spend about 15 minutes exploring answers to each question. There are six focus questions and additional time to give last comments in conclusion. You do not need to answer any questions you do not want to answer and you may leave at any time without giving a reason.
- An audio recorder will be used to record your comments. Your comments will be transcribed and stored in a confidential, secure location at the University of Auckland and destroyed ten years post-publication.
- This study aims to understand why parents decide to disclose or not disclose information to their children about illness. It also seeks to inform the researcher of appropriate ways to go about researching patients’ views.

Risks & benefits

- Besides contributing to our knowledge of what it means to be a part of a family/whānau receiving PPC, the participating families may benefit from expressing themselves in the focus group and meeting others who have gone through or are going through similar experiences. They may feel more in control by knowing that their voices are being heard. Awareness of families/whānau’s thoughts and feelings may lead to guidelines that will mutually benefit children, families/whānau, and medical teams. Participating families may also benefit from knowing they can do something which may be used to help whānau and families like them in the future.
- Though the intention of this focus group is not therapeutic, it may help families/whānau of patients to speak with and listed to other families/whānau of patients.
- During the focus groups, participants may express needing psychological help. The researcher will immediately contact the appropriate network within Starship. She has five years of experience with families at a children’s hospice. Should any unusual or harmful information be discovered, she will discuss the situation with the PPC team.

< PPC Family/Whānau Focus Groups >
Participant Information Sheet Version 2, 23/10/09
Her supervisor, clinician Glynn Owens will accompany her at the focus groups to assure that proper care is offered. Participants will be given a letter at the end of the session which will include a list of family psychologists and resources.

- Families will be reimbursed with petrol vouchers for their transportation and parking costs.

Compensation

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

Participation

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect your future care or treatment.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

You may leave the focus group at any time and you do not have to answer all the questions.

Participation in this study will be stopped should any harmful effects appear or if the clinician present or PPC team feels in is not in the participant’s best interests to continue

General Information

- At the end of the study, the research results (without names or identifiers) will be organised in a journal article, which will be potentially submitted to peer reviewers and eventually submitted for publication. The results will be published and presented, firstly at the University of Auckland and then to a wider audience of health professionals interested in working in the field of children's end of life care. The results will also be compiled in Erin’s Doctoral Thesis with the results of related studies. Participating families/whanau will be informed of the study results upon the completion of the project, though their individual anonymity will be maintained if they consent and disclose their address to the researcher.
- Participants will be referred to a family psychologist if necessary.
- Please contact the principal investigator, Erin Gaab at e.gaab@aublalnd.ac.nz or 09 373 7599 extension 87818 for more information.
- Unfortunately, interpreters cannot be provided to participants. Participants must be competent in English.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.
Confidentiality

No material which could personally identify you will be used in any reports on this study.

- Participants’ information will be stored in a locked cabinet in a room with restricted access at the University of Auckland.
- A professional transcriber who signs a confidentiality agreement may be hired to convert your words into text.
- Information will be destroyed and deleted six months after publication.
- If significant issues arise from the focus groups, these will be discussed first with Psychologist Glynn Owens and if necessary with the Paediatric Palliative Care Team to ensure the safety of participants.
- Please contact the principal investigator, Erin Gaab at e.gaab@auckland.ac.nz or 09 373 7599 extension 87818 for more information.
- Notes may only be checked by those present at the focus group: Erin Gaab and Professor Glynn Owens.

Results

- If you would like to participate and receive the results of the study, please leave your name and contact information with the principal investigator. She will ensure that you are informed of the findings upon completion of the analysis and publication.
- There may be a delay between the time at which your focus group is conducted and the results are published, as transcription, analysis and interpretation may take a long time.
- If you would like to discuss the outcomes of the study with the principal investigator, you may contact her after the study.

Who should I contact if I have further questions?

If you have any questions about the study, do not hesitate to contact the Principal Investigator, Erin Gaab, or Glynn Owens, Study coordinator, ph 09 737 7599 extn. 88845.

If you have any questions or concerns about your rights as a participant in a research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdcc.org.nz

For Maori health support at the ADHB, or to discuss any concerns or issues regarding this study, please contact Mata Forbes RGON, Maori Health Services Co-ordinator / Advisor, 5th Level, GM Suite, Auckland City Hospital. Tel 307 4949 extn. 23939 or Mobile 021 348 432

This study has received ethical approval from the Northern X Regional Ethics Committee.

Please feel free to contact the researcher if you have any questions about this study.

Thank you for making the time to read about and consider taking part in this study.

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Appendix 23

Consent Form

Name of Study: Exploring the Voices of Parents and Whānau, Increasing our understanding of families' experiences by listening to families

- I have read and I understand the information sheet dated 23/10/09 for volunteers taking part in the study designed to ____________________________, I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use family/whānau support or a friend to help me understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time. This will in no way affect my health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that I may leave the study, if it should appear harmful to me.
- I understand the compensation provisions for this study which only involve reimbursement for my transportation costs.
- I know who to contact if I have any side effects to the study.
- I know who to contact if I have any questions about the study.

I consent to my voice being audio-taped. YES/NO

I wish to receive a copy of the results YES/NO

A significant delay may occur between data collection and publication of the results.

I would like the researcher to discuss the outcomes of the study with me YES/NO

________________________________________ (full name) hereby consent to take part in this study.
Signature ___________________ Date ________________

Project explained by __________________________________________

Project role __________________________________________
Signature ___________________ Date ________________

N.B. There should be three complete copies of the signed Research Consent Document:
- Copy for the participant
- Copy for the clinical record
- Original for the Study Master File.

< PPC Family/Whanau Focus Groups >
Consent Form Version 2, 23/10/2009
Not telling: Parents did not tell their children to avoid negative changes. They wanted to protect them from...

- **Avoiding negative changes in emotions**
  - losing hope (n=7)
  - blame/regret (n=2)
  - negative emotional reactions (n=13)

- **Avoiding negative changes in perceptions**
  - stigma about death from others / changing lifestyle (n=11)
  - losing innocence (n=9)

- **Avoiding negative changes in relationships**
  - as per others’ recommendations (n=6)
  - the child did not want to discuss (n=11) / an unnecessary conversation (n=9)
  - being the bearer of bad news by telling children in the wrong way (n=7)

- **The unknown (to parent)**
  - (n=6)
Appendix 25

Telling the children: Parents talked about death to prepare them by providing them with...

Unavoidable: patient already knew; elephant in the room (n=8)

Family is always open and honest with children (n=14)

Acknowledge

In response to the children (not denied or forced) (n=13)

Guilt: do not lie or trick the child (n=4)

for children and their friends’ questions (n=5)

Teach

to reassure children (decrease fear) (n=12)

to help understand why (n=9)

to appreciate the less fortunate and help the family (n=8)

to break the news gradually (n=9)

to allow children to express their emotions (n=9)

to let children work through their issues themselves (n=4)

to grant permission to die (n=2)

to grant pre- and post-death wishes (n=14)

Enable

the advice and support of others (n=14)

hope, willpower, strength and peace of mind (n=8)

the patient can handle the situation maturely (n=8)

Acknowledgement

Unavoidable; patient already knew; elephant in the room (n=8)

In response to the children (not denied or forced) (n=13)

Guilt: do not lie or trick the child (n=4)

for children and their friends’ questions (n=5)

Teach

to reassure children (decrease fear) (n=12)

to help understand why (n=9)

to appreciate the less fortunate and help the family (n=8)

to break the news gradually (n=9)

to allow children to express their emotions (n=9)

to let children work through their issues themselves (n=4)

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to grant pre- and post-death wishes (n=14)

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to let children work through their issues themselves (n=4)

to grant permission to die (n=2)

to grant pre- and post-death wishes (n=14)

Enable

the advice and support of others (n=14)

hope, willpower, strength and peace of mind (n=8)

the patient can handle the situation maturely (n=8)
Perceptions of Life and Death in Paediatric Palliative Care

Appendix 26

Participant Information Sheet (Primary Caregiver)

Name of the study *The Voices of PPC Patients and Siblings*

<table>
<thead>
<tr>
<th>Principal Investigator:</th>
<th>Erin Gaab</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhD student</td>
<td></td>
</tr>
<tr>
<td>Department of Psychology</td>
<td></td>
</tr>
<tr>
<td>Tamaki Campus</td>
<td></td>
</tr>
<tr>
<td>University of Auckland</td>
<td></td>
</tr>
<tr>
<td>Private Bag 92019</td>
<td></td>
</tr>
<tr>
<td>Auckland, New Zealand</td>
<td>+64 9 373 7599 ext. 87818</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supervisor:</th>
<th>Glynn Owens</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor of Psychology</td>
<td></td>
</tr>
<tr>
<td>Tamaki Campus</td>
<td></td>
</tr>
<tr>
<td>University of Auckland</td>
<td></td>
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<tr>
<td>Private Bag 92019</td>
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<tr>
<td>Auckland, New Zealand</td>
<td></td>
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<tr>
<td>+64 9 373 7599 ext. 86845</td>
<td></td>
</tr>
</tbody>
</table>

You are invited to take part in a research study about understanding the experiences of children involved in paediatric palliative care. It aims to give children a voice in the current PPC literature.

Please take your time to think about it and decide whether you wish to take part in it. Taking part is completely voluntary (your choice) and if you decided you do not wish to take part, it will not affect your continuing healthcare in any way.

**Why are you being asked? / what it all about?**

- Children at the end of their lives spend a lot of time in their hospital rooms, alone or with adults. The most human contact they have with people is generally with parents, nurses and doctors. All the people they interact with have strong opinions about their welfare and situations which may prevent children from expressing their honest opinions to the adults in their lives. As a non-biased, silent medium, a blank journal with a lock and key or audio recorder will allow children in hospital to express whatever it is they are not willing to talk about with the adults in their lives. Rather than subjective, involved opinions of adults who have cared for children to tell us what needs the children have, the voices of children themselves will enable us to extract patterns of their genuine concerns.

- The study will take place when you feel it is appropriate for your child to take part and will last for one month.

- You are invited to allow your child/children to participate because you have a child who is between the ages of 10 and 20 and is receiving paediatric palliative care or has a terminal illness. Ten to thirty PPC patients and siblings who fit these criteria will be participating. Only children fluent in English with adult whanau members who consent to their participation are eligible to participate.

**What happens during the study?**

- This journaling project will involve two required visits each participant: one in which the researcher visits the child to obtain informed consent, deliver the journal or tape recorder and give instructions and one in which the researcher returns to the child to collect it.

- After receiving the permission of the child(ren)’s PPC providers and family (who have been fully informed of the content and aims of the study), the child(ren) will receive the medium (blank 100-page journal or tape recorder) they prefer. They will be informed:

< *The Voices of PPC Patients and Siblings* >

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- “This is a study to find out what children think. This is a diary which will be read by Erin, the person doing this study, and may help children in the future. You can say whatever you would like me to hear. You can talk about how you are feeling, what you would like to do, how your day went, or anything else you want to say. You can draw pictures if you would like, also. If you want to stop writing in it at any time, you can. Some other children may be doing the same thing as you and when they are done; their journals will be put in the same place as yours. I will take care of your journals and keep them. You will not get your journal back after you are done with it and nobody will know who wrote it. I will be back in one month to get your journal.

- There is a short list of questions inside might help get you started writing, but you do not have to answer them. If you have an audio recorder, you may record yourself, listen to your recordings, erase and re-record yourself speaking.

- If putting down your thoughts makes you sad and you want to talk to someone else, there are people who talk to children all the time. Please ring or email Erin, whose name is posted inside the journal/ on the recorder if you feel this way and he or she will get someone to help you [a psychologist, chaplain, etc.]

- The study does not mention the severity of the child’s illness or suggest that the child or his or her sibling is at the end of his or her life.

- The journals and are for the children’s use only, and if you wish to see them, you must ask your child. However, the purpose of this study is to enable future families and clinicians to better predict the needs of paediatric palliative patients and their siblings.

- At the end of each week in which the child holds a journal or recorder, they will be asked, (1) “Would you like another [journal or recorder]?”; (2) “Did you find it useful or helpful in any way?” and, if yes, (3) “How was it useful?”

- They will be allowed to receive up to four diaries/ journals (one per week for one month).

- Upon the conclusion of the study, the journals and recordings will become the property of the researcher. They will only be viewed by the researcher and her confederates at the university and on the PPC team if significant recordings appear. The researcher will transcribe the tapes and writing.

- Participant information and raw data will be kept in a locked cabinet in a secure location with restricted access at the University of Auckland. They will be destroyed six months post-publication.

- Grounded theory, which recognises children as people in their “own right” will be used to analyse this research. Children’s perceptions of their childhood will help researchers and clinicians to understand it through their eyes. The theory will emerge from the data collected.

Risks & benefits

- Besides contributing to care providers’ and PPC researchers’ knowledge of the needs of children affected by it, the children may benefit from expressing themselves in the journals. They may experience a feeling of freedom and control from knowing that their voices are being heard and that they are contributing toward making a positive change. As mentioned previously, many terminally ill paediatric patients make decisions based on caring about others (Hinds et al., 2005). This project provides a subjective outlet for feelings, concerns, and emotions of patients and siblings. It is anticipated that an increased awareness of children’s subjective thoughts and feelings will lead to an increased awareness and guidelines that will mutually benefit children, whanau, and medical teams. Participants’ whanau and families may also benefit from knowing they can do something during difficult situation which may be used to help whanau and families like them in the future.

- Many researchers hesitate to recognise children as accurate moderators of their own experiences partly because of issues relating to adult/child power relationships and adult judgements about social and cognitive abilities (France et al., 2000). This
Perceptions of Life and Death in Paediatric Palliative Care

research seeks to empower children and enable adults to understand their perspectives within the PPC setting.

- Unknown issues could arise during the participants’ recordings in their journals, such as participants’ expressions of being depressed or needing something immediately that she or he is too embarrassed to ask for. Since the journals will be collected weekly and the recordings will be listened to at least weekly, E.M.G. will be able to act immediately. E.M.G. has five years of experience playing and working with children at a children’s hospice as well as numerous other experiences helping children in medical and other settings. Should any unusual or harmful information be discovered, she will discuss the situation with the PPC team. Attached to the tape recorders and journals, a list of resources will be provided to participants including a list of numbers at which they can reach child and family psychologists and resources.

Compensation

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

Participation

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part, this will not affect future care.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

Participation in this study will be stopped should any harmful effects appear or if the doctor feels in is not in the participant’s best interests to continue

General Information

- At the end of the study, the research results (without names or identifiers) will be organised in a journal article, which will be potentially submitted to peer reviewers and eventually submitted for publication. The results will be published and presented, firstly to peers at the University of Auckland and then to a wider audience of health professionals interested in working in the field of children’s end of life care. The results will also be compiled in E.M.G.’s Doctoral Thesis with the result of related studies. Whanau will be informed of the study results upon the completion of the project, though their child’s anonymity will be maintained. They will be sent a summary of the research if they consent and disclose their address to the researcher.
- Participants will be referred to a family psychologist if necessary.

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Perceptions of Life and Death in Paediatric Palliative Care

- Please contact the principal investigator, Erin Gaab at e.gaab@auckland.ac.nz or 09 373 7599 extension 87818 for more information.
- Unfortunately, interpreters cannot be provided to participants. Participants must be competent in English.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

Confidentiality

No material which could personally identify you will be used in any reports on this study.
- Participants’ information will be stored in a locked cabinet in a room with restricted access at the University of Auckland.
- Information will be destroyed and deleted six months after publication.
- If significant issues arise from the focus groups, these will be discussed first with Psychologist Glynn Owens and if necessary with the Paediatric Palliative Care Team to ensure the safety of participants.
- Please contact the principal investigator, Erin Gaab at e.gaab@auckland.ac.nz or 09 373 7599 extension 87818 for more information.
- Notes may only be checked by the principal investigator and her supervisors, Professors Glynn Owens and Roderick MacLeod.

Results

- If you would like to participate and receive the results of the study, please leave your name and contact information with the principal investigator. She will insure that you are informed of the findings upon completion of the analysis and publication.
- There may be a delay between the time at which you participate and the results are published, as transcription, analysis and interpretation may take a long time.
- If you would like to discuss the outcomes of the study with the principal investigator, you may contact her after the study.

Who should I contact if I have further questions?

ADHB Patient Information Sheet Version X, 28/08/09

If you have any questions about the study, do not hesitate to contact the Principal Investigator, Erin Gaab, or Glynn Owens, Study coordinator, ph 09 737 7599 ext. 86845.

If you have any questions or concerns about your rights as a participant in a research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

< The Voices of PPC Patients and Siblings >
Patient Information Sheet Version 1, 28/08/2009
Perceptions of Life and Death in Paediatric Palliative Care

For Maori health support at the ADHB, or to discuss any concerns or issues regarding this study, please contact Mata Forbes RGON, Maori Health Services Co-ordinator / Advisor, 5th Level, GM Suite, Auckland City Hospital. Tel 307 4949 extn. 23939 or Mobile 021 348 432.

Include either This study has received ethical approval from the Northern X Regional Ethics Committee. Please feel free to contact the researcher if you have any questions about this study. Thank you for making the time to read about, and consider taking part in this study.
Appendix 27

Participant Information Sheet

The Voices of Patients and Siblings

Hello possible participant,
Are you between the ages of 10 and 20?
Do you have a serious illness or have a brother or sister who has one?
Do you speak English?

If you answered yes to all of those questions, I would like to invite you to help me and others understand your experience as a young person or sibling of a young person who is very unwell. This research study aims to give children and teens a voice in the things that doctors and caregivers read.

Who wrote this?
My name is Erin. I talked, played and worked with people like you at a children’s hospice for five years and now hope to help families in NZ through research.

Do I have to take part?
No. Please take your time to think about it and decide whether you wish to take part. Taking part is completely your choice. You may stop at any time without a reason. Not participating or stopping will not affect your health care. Your participation in this study will be stopped if you, my supervisors, a team at Starship, or I feel it is not in your best interest to continue.

Who else might get a letter like this?
Ten to thirty people who answered "yes" to the questions above will take part. Only fluent English-speakers with family/whanau who say it is okay to participate may.

What happens during the study?
You will receive a blank journal with a lock or an audio recorder. You may use it to say anything you would like others to know but don’t want to talk about directly.

You will be told: “This is a study to find out what young people think. This is a diary which will be read by me, Erin, and may help children in the future. I would like to use your information for my big research project (PhD). You can say whatever you would like me to hear. You can talk about how you are feeling, what you would like to do, how your day went, or anything else you want to say. You can draw pictures if you would like. When you finish I will put your journal in the same place as other participants. I will take care of your journals and keep them. You will not get your journal back after you are done with it and nobody will know who wrote it. I will be back in one week to get your journal.”

There are a few short questions inside might help get you started writing, but you do not have to answer them. If you have an audio recorder, you may record yourself, listen to your recordings, erase and re-record yourself speaking.

The journal is for your use only. Others should ask you if they wish to see it.

At the end of each week in which you hold a journal or recorder, you will be asked, (1) “Would you like another [journal or recorder]?” (2) “Did you find it useful or helpful in any way?” and, if yes, (3) “How was it useful?”

< The Voices of PPC Patients and Siblings >
Patient Information Sheet Version 2, 23/10/2009
You are allowed to receive up to four diaries/journals (one per week for one month).

- Sadly, interpreters cannot be provided. You must write or speak English.
- Upon the conclusion of the study, the recordings will become the property of me (Erin), the researcher. I will type up your words from the recorder or diary.
- Your information will be kept in a locked cabinet in a secure place that only I can get to at the University of Auckland. It will be destroyed ten years from now or ten years after you turn 16.

What might happen to me?

- Besides helping care providers and researchers learn about your needs, you may benefit from expressing yourself in the journal. Your voice will be heard and you may help contribute toward making a positive change for others like you.
- You may let out your feelings, concerns, and/or emotions.
  - If you need something immediately, I may be able to help you. If I read about something that might harm you, I might discuss it with someone at Starship. Only then may your diary be viewed by others at the hospital or university. Attached to your recorder or diary, a list of resources will be provided to you including a list of numbers at which you can reach child and family psychologists and resources.

What if I have questions or concerns?

- If you want to talk to someone else, I know counselors who talk to young people all the time. Please ring or email me, Erin. I can get someone to help you [a psychologist, chaplain, or someone else].

What will happen after the study?

- At the end of the study, I will organize the research results (without names or identifiers) in an article, which I hope to publish. The results will be presented at the University of Auckland and to health professionals. The results will also be compiled in my Doctoral Thesis with related studies. Families/whanau will be informed of the study results after the project finishes, though they will not know which part of the research you contributed to. They will be sent a summary of the research if they wish and give their contact information to me.
- You may be referred to a family psychologist if necessary.

A friend, family or whanau support may help you understand this study.

Will people know what I wrote?

- No material which others could tell was written or said by you will be used in reports on this study.
- Participants' information will be stored in a locked cabinet in a room with restricted access at the University of Auckland.
- You will be given the option of sharing your journal recordings with a family/whanau member after you have completed your participation. If you do not sign the final consent form, your data will remain the property of the researcher and nobody else will know what you wrote.

Will I get to see the results?

- If you would like to participate and receive the results of the study, please leave your name and contact information with me, Erin. I will tell you about what I learn from interviewing you and others after I finish.

< The Voices of PPC Patients and Siblings >

Patient Information Sheet Version 2, 23/10/2009
There may be a delay between the time at which you participate and the results are published, as writing the paper may take a long time.

If you would like to talk about the results of the study with me, please contact me after the study is finished.

Who should I contact if I have further questions?

If you have any questions about the study, please do not hesitate to contact:

**Principal Investigator:** Erin Gaab  
PhD student  
Department of Psychology  
Tamaki Campus  
University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
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**Supervisor:** Glynn Owens  
Professor of Psychology  
Department of Psychology  
Tamaki Campus  
University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
+64 9 373 7599 ext. 86845

If you have any questions or concerns about your rights as a participant in a research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050  
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)  
Email (NZ wide): advocacy@hdc.org.nz

For Maori health support at the ADHB, or to discuss any concerns or issues regarding this study, please contact Mata Forbes RN, Maori Health Services Co-ordinator / Advisor, 5th Level, GM Suite, Auckland City Hospital. Tel 307 4949 extn. 23939 or Mobile 021 348 432

This study has received ethical approval from the Northern X Regional Ethics Committee.

Please feel free to contact the researcher if you have any questions about this study.

Thank you for making the time to read about, and considering taking part in, this study.

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*The Voices of PPC Patients and Siblings*  
Patient Information Sheet Version 2, 23/10/2009
Appendix 28

Consent Form

Name of Study The Voices of Patients and Siblings

- I have read and I understand the information sheet dated 10/23/09 for volunteers taking part in the study designed to

- I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use family/whanau support or a friend to help me understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time. This will in no way affect my health care.
- I understand that my participation in this study is confidential and that my personal information will not be used in reports on this study.
- I understand that the study will be stopped if it seems harmful to me.
- I know who to contact if I have any side effects to the study.

I consent to being audio-taped. YES/NO
I would like the researcher to discuss the outcomes of the study with me YES/NO

__________________________________________________________________________

I ____________________ (full name) hereby consent to take part in this study.

Signature ___________________________ Date __________________

Project explained by __________________________

Project role __________________________

Signature ___________________________ Date __________________

N.B. There should be three complete copies of the signed Research Consent Document:
- Copy for the participant
- Copy for the clinical record
- Original for the Study Master File.

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Guiding Questions:

- Which emotion (or bear) do you feel like today? Why?
- What should people know about young people who are unwell?

If you have any questions about this study, please email e.gaab@auckland.ac.nz or ring her at 027 611-4744. If she cannot help you, she will get someone for you who can.

Guiding Questions:

- Which emotion (or bear) do you feel like today? Why?
- What should people know about brothers of young people who are unwell?

If you have any questions about this study, please email e.gaab@auckland.ac.nz or ring her at 027 611-4744. If she cannot help you, she will get someone for you who can.

Guiding Questions:

- Which emotion (or bear) do you feel like today? Why?
- What should people know about sisters of young people who are unwell?

If you have any questions about this study, please email e.gaab@auckland.ac.nz or ring her at 027 611-4744. If she cannot help you, she will get someone for you who can.
Appendix 30

Review and Optional Data Sharing Consent Form

Name of Study The Voices of Patients and Siblings

Review:
1. Would you like another journal or recorder? YES/NO
2. Did you find it useful or helpful in any way? YES/NO
3. If yes, how was it useful? ____________________________________________
   ____________________________________________

Optional Data Sharing:
- I wish to make my diary or audio recordings available to my family/whanau member.
- I understand that there may be a delay between when my diary is collected and when
  my family/whanau member is able to access it (months to years).
- I understand that this person may choose to share my recordings with others.

I consent to allowing the researcher to make it available to the following individual:

________________________________________

I would like the researcher to ask that person to keep my information private. YES/NO

________________________________________

I ______________________ (full name) hereby consent to allow the above named to
access to my information.

Signature ___________________________ Date ___________________________

Data sharing explained by ________________________________

Project role ________________________________

Signature ___________________________ Date ___________________________

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Participant Information Sheet (Parent)

Name of the study Understanding Siblings’ Voices

**Principal Investigator:** Erin Gaab  
PhD student  
Department of Psychology  
Tamaki Campus  
University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
+64 9 373 7599 ext. 87818

**Supervisor:** Glynn Owens  
Professor of Psychology  
Department of Psychology  
Tamaki Campus  
University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
+64 9 373 7599 ext. 86845

You are invited to take part in a research study about siblings’ preferred level of involvement in their unwell siblings’ end-of-life care and their perceptions.

Please take your time to think about it and decide whether you wish to take part in it. Taking part is completely voluntary (your choice) and if you decided you do not wish to take part, it will not affect your continuing healthcare in any way.

**What it all about?**

- Siblings of unwell children are often left out of the care. When the ill child goes into the hospital for treatment, the siblings are often left in the waiting room. All the people children involved with unwell children interact with have strong opinions about their welfare and situations. These opinions may prevent children from expressing their honest opinions to the adults in their lives. Rather than subjective, involved opinions of adults who have cared for children to tell us what needs the children have, the voices of children themselves will enable us to extract patterns of their genuine concerns.
- This sibling interview project will involve one required visit each participant. In that session the researcher visits the child to obtain informed assent and conducts the interview with the child.
- 10-30 PPC patients’ siblings between the ages of 10 and 20 who are competent in English will be interviewed.

**What happens during the study?**

- After receiving the permission of the child’s PPC providers and family (who have been fully informed of the content and aims of the study), the child will be informed: “This is a study which intends to give children a voice. I would like to hear about your thoughts and opinions. If talking to me makes you sad and you want to talk to someone else, there are people who would love to talk to you. Please tell your doctor if you feel this way and he or she will get someone to help you [a psychologist, chaplain, etc].” The interview may contain questions similar to the following:
- “Please answer all questions as completely and honestly as possible. If there is a question you do not wish to answer, please just let me know and we will skip it. You may withdraw from the study at any time...”
- What are your earliest memories of your sibling [PPC patient]?

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2. How does being a sister/brother make you feel?
3. What is your favourite thing to do with [PPC patient]?”

The questions have been designed with the help of play therapists and the Starship PPC team.

- The interview may take place in the Child Cancer Foundation Family Support Building, the child’s home, or another place mutually agreed upon as appropriate by the researcher, child and child’s family.
- Children will not be given a limit, though the interview will be structured to last between 45 minutes and 1 hour and 15 minutes. Participants will be given the option of editing their transcripts upon request.
- Audio recording devices will be used to ensure the accuracy of the interview notes, though they may be turned off at any time.
- The interviewer and principal researcher will transcribe the audio recordings.
- Children will be given the option of editing their transcription in the week following its conduction and will have two weeks to edit their words.
- The audio recordings and transcription notes will be destroyed six years post-publication.

Risks & benefits

- Siblings of very unwell children have been reported to be ignored and in need of an outlet for support (Kubler-Ross, 1983). This project provides not only a way for children to help other children by contributing to the research, but also gives them a subjective outlet for feelings, concerns, and emotions of patients and siblings.
- Children and adolescents of this age who are dealing with situations involving life-limiting illnesses may feel inhibited from expressing needs and desires to their caregivers. They may feel that their concerns will only burden them and that hiding sad emotions will help their families/whanau. They may hide feelings and expressions that could otherwise benefit them or their families in the caring of the patient. This project will not only allow current siblings of unwell children to express what they may be holding back from their caregivers, but it will benefit PPC patients and their siblings in the future by creating awareness of those issues before they arise.
- Unknown issues could arise during the participants’ interviews, such as participants disclosing feelings of depression or needing something immediately that they are too embarrassed to ask for. Since the principal investigator will conduct all of the interviews, E.M.G. will be able to act immediately. E.M.G. has five years of experience playing and working with children at a children’s hospice as well as numerous other experiences helping children in medical and other settings. Should any unusual or harmful information be discovered, she will discuss the situation with the PPC team. In the letter of thanks she gives to participants following the interview, a list of resources will be provided including a list of numbers at which they can reach child and family psychologists and the skewlight website.
- The Paediatric Palliative Care Team at Starship Children’s Hospital in Auckland is the first network the researcher will contact directly to seek advice for dealing with immediate issues. Outside child and family psychologists will also be available to deal with emergencies.
- Families will be reimbursed with petrol vouchers for their transportation and parking costs if they travel to participate.

Compensation

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In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

Participation

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect any future care.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

You may stop the interview at any time and you do not have to answer all the questions.

Participation in this study will be stopped should any harmful effects appear or if the doctor feels it is not in the participant’s best interests to continue.

General Information

- At the end of the study, the research results (without names or identifiers) will be organised in a journal article, which will be potentially submitted to peer reviewers and eventually submitted for publication. The results will be published and presented, firstly to peers at the University of Auckland and then to a wider audience of health professionals interested in working in the field of children’s end of life care. The results will also be compiled in E.M.G.’s Doctoral Thesis with the result of related studies. Families/whanau will be informed of the study results upon the completion of the project, though their individual anonymity will be maintained. They will be sent a summary of the research if they consent and disclose their address to the researcher.
- Participants will be referred to a family psychologist if necessary.
- Please contact the principal investigator, Erin Gaab at e.gaab@auckland.ac.nz or 09 373 7599 extension 87818 for more information.
- Unfortunately, interpreters cannot be provided to participants. Participants must be competent in English.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

Confidentiality

No material which could personally identify you will be used in any reports on this study.

- Participants’ information will be stored in a locked cabinet in a room with restricted access at the University of Auckland.
- Information will be destroyed and deleted six months after publication.

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- If significant issues arise from the interviews, these will be discussed first with Psychologist Glynn Owens and if necessary with the Paediatric Palliative Care Team to ensure the safety of participants.
- Please contact the principal investigator, Erin Gaab at e.gaab@auckland.ac.nz or 09 373 7599 extension 87818 for more information.
- Notes may only be checked by those present at the focus group: Erin Gaab and Professor Glynn Owens.

Results

- If you would like to participate and receive the results of the study, please leave your name and contact information with the principal investigator. She will inform you of the findings upon completion of the analysis and publication.
- There may be a delay between the time at which your child’s interview is conducted and the results are published, as transcription, analysis and interpretation may take a long time.
- If you would like to discuss the outcomes of the study with the principal investigator, you may contact her after the study.

Who should I contact if I have further questions?

ADHB Patient Information Sheet Version 1, 28/08/09

If you have any questions about the study, do not hesitate to contact the Principal Investigator, Erin Gaab, or Glynn Owens, Study coordinator, ph 09 737 7599 ext. 86845.

If you have any questions or concerns about your rights as a participant in a research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

For Maori health support at the ADHB, or to discuss any concerns or issues regarding this study, please contact Mata Forbes RGN, Maori Health Services Co-ordinator / Advisor, 5th Level, GM Suite, Auckland City Hospital. Tel 307 4949 extn. 23939 or Mobile 021 348 432

Include either
This study has received ethical approval from the Northern X Ethics Committee.

Please feel free to contact the researcher if you have any questions about this study.

Thank you for making the time to read about, and consider taking part in this study.
Appendix 32

Participant Information Sheet

Hello possible participant,

Are you between the ages of 10 and 20?
Do you have a brother or sister who has a serious illness?
Do you speak English?

If you answered yes to all three of those questions, I would like to invite you to help me and others understand your experience as a sister or brother of a young person who is very unwell. This research study aims to help doctors and caregivers understand how involved young people want to be in their unwell brothers’ or sisters’ care and how they feel people treat them now.

Who wrote this?
Hi, my name is Erin. I talked, played and worked with people like you at a children’s hospice for five years. Now I am studying families like yours.

Do I have to take part?
No. Please take your time to think about it and decide whether you wish to take part. Taking part is completely your choice. You may stop at any time without a reason. Not participating or stopping will not affect your health care. Your participation in this study will be stopped if you, my supervisors, the PPC team, or I feel it is not in your best interest to continue.

Who else might get a letter like this?
10-30 English-speaking brothers and sisters of unwell children (who are between the ages of 10 and 20) will be interviewed.

Why don’t you just ask my family/whānau?
Instead of asking adults who care for young people with unwell brothers and sisters to tell us their needs, I want to know what your real concerns are from you.

What happens during the study?
This sibling interview project involves me visiting you to explain this study and ask you some questions.
After receiving the permission of your doctors and family (who have been told about this study), I will tell you, "This is a study which intends to give young people a voice. I would like to hear about your thoughts and opinions." The interview may contain questions like:
"Please answer all questions as completely and honestly as possible. If there is a question you do not wish to answer, please just let me know and we will skip it. You may leave the study at any time...
1. Let’s draw a family tree. Who else do you see often? Do you have any pets?
2. Tell me something about your brother/sister. What do you like to do with him/her?"

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The interview may take place in the Child Cancer Foundation Family Support Building, your home, or another place that you, me, and your family agree is okay.

How long will it take?
- You will not be given a time limit, though the questions are meant to take between 45 minutes and 1 hour and 15 minutes to answer.

How will Erin remember what I said?
- An audio recorder will be used, though it may be turned off at any time.
- I will write down what you said later from your audio recording.
- Your information will be kept in a locked cabinet in a secure place that only I can get to at the University of Auckland. It will be destroyed ten years from now or ten years after you turn 16.

What could happen to me?
- This project allows you to help children by contributing to research. It gives you an outlet for feelings, concerns, and emotions.
- Issues we can’t expect could come up during your interview, such as you needing something immediately that you are too embarrassed to ask for. Since I (Erin) will conduct all of the interviews, I will be able to act immediately. I have played, chatted and worked with children and teenagers at a children’s hospice. If any harmful information or immediate issues come up, I will discuss them with a team at Starship. After the interview, I’ll give you a list of resources.
- Outside child and family psychologists will also be available to deal with emergencies and you may be referred to a family psychologist if necessary.
- Families will be given petrol vouchers for their transportation and parking costs if they travel to participate.

What else should I know?
- At the end of the study, I will organise the research results (without names or identifiers) in an article, which I hope to publish. The results will be presented at the University of Auckland and to health professionals. The results will also be compiled in my Doctoral Thesis with related studies. Families/whānau will be informed of the study results after the project finishes, though they will not know which part of the research you contributed to. They will be sent a summary of the research if they wish and give their contact information to me.

You may have a friend, family or whānau support help you understand this study.

Will anyone know that I said what I did?
No, no material which others could tell was written or said by you will be used in reports on this study.

- Erin will organise 10-30 participants’ data as a large group so that no individual will be identified. Specific personal identifiers will not be written about.
- If significant issues arise in your diary, Erin will discuss them with her supervisor Glynn Owens and if necessary with the PPC Team to ensure your safety.

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Erin will give the interview recording to a professional typist who agrees to keep your information a secret. She or he will type your words onto paper. Notes may only be checked by Erin and her supervisors.

**Will I get to see the results?**

If you would like to participate and receive the results of the study, please leave your name and contact information with me, Erin. I will tell you about what I learn from interviewing you and others after I finish.

There may be a delay between the time at which you participate and the results are published, as writing the paper may take a long time.

If you would like to talk about the results of the study with me, please contact me after the study is finished.

**Who should I contact if I have further questions?**

If you have any questions about the study, do not hesitate to contact:

**Principal Investigator:** Erin Gaab  
PhD student  
Department of Psychology  
Tamaki Campus  
University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
+64 9 373 7599 ext. 87818

**Supervisor:** Glynn Owens  
Professor of Psychology  
Department of Psychology  
Tamaki Campus  
University of Auckland  
Private Bag 92019  
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5th Level, GM Suite, Auckland City Hospital. Tel 307 4949 extn. 23939 or  
Mobile 021 348 432

This study has received ethical approval from the Northern X Ethics Committee.

**Please feel free to contact the researcher if you have any questions about this study.**  
Thank you for making the time to read about, and consider taking part in this study.

*Understanding Siblings’ Voices*  
Patient Information Sheet Version 2, 23/10/2009
Appendix 33

Consent Form

Name of Study Understanding Siblings’ Voices

- I have read and I understand the information sheet dated 23/10/09 for volunteers taking part in the study designed to ___________________________. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use family/whanau support or a friend to help me understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- I have had this project explained to me by ___________________________.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that the interview will be stopped if it seems harmful to me.
- I understand that a professional transcriber will type up my information.
- I know who to contact if I have any questions about the study.

I consent to my interview being audio-taped. YES / NO

I wish to receive a copy of the results YES / NO

A delay may occur between data collection and publication of the results.

I would like the researcher to discuss the outcomes of the study with me YES / NO

I ___________________________ (full name) hereby consent to take part in this study.

Signature ___________________ Date ________________

Project explained by ____________________________

Project role ____________________________

Signature ___________________________ Date ________________

N.B. There should be three complete copies of the signed Research Consent Document:

- Copy for the participant
- Copy for the clinical record
- Original for the Study Master File.

Understanding Siblings’ Voices

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Appendix 34

Questionnaire

Name of Study Understanding Siblings’ Voices

This is a study which intends to give young people a voice. I would like to hear about your thoughts and opinions. This project is for my PhD on young people’s perceptions of kids who are very unwell. Please answer all questions as completely and honestly as possible. There are no right or wrong answers to any of the questions I will ask you. If there is a question you do not wish to answer, please just let me know and we will skip it. You may stop the study at any time or ask me to turn off this recorder. There’s a squeeze ball for you to hold or play with if you’d like... just for fun. There are some markers and paper on the table if you’d like to write or draw anything instead of saying it.

Age: 10 11 12 13 14 15 16 17 18 19 20
Sibling’s Age: 10 11 12 13 14 15 16 17 18 19 20

Ethnicity: ____________________ Gender: ________
Sibling’s Disease: ____________ Sibling’s Gender: ______
Time since Diagnosis: __________

1. Let’s draw a family tree.
   a. Who else do you see often? Do you have any pets?

2. Tell me something about your brother/sister. What do you like to do with him/her?
   a. When you talk to your friends about your brother/sister, what do you tell them about him/her?

3. How do you get on with your brother or sister?
   a. Has it always been that way?

4. If I was to ask your brother or sister to tell me about you, what do you think he/she would say?
   a. What might they say if I asked them to tell me about you in three words?
   b. If I asked your brother/sister what you do for him/her, what would he/she say?

5. What are some things you and your brother/sister have had fights about?

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6. What is your least favourite thing about being a brother/sister? (= for older kids)

7. If you have other siblings, what is different about your relationship with [PPC patient]?

8. How is your brother/sister doing?

9. What is tough about having an unwell brother/sister?
   a. Other brothers/sisters find... (less time with mum and dad, etc.) to be hard. What do you think about that?

10. Is there anything you worry about with him/her?
   a. What do you do when you’re worried about him/her?
   b. Who do you talk to?
   c. Do you use facebook/bebo/myspace? If so, how (messages, wall posts)?

11. What do you remember about being told about your brother’s/sister’s illness?
   a. What do you remember about the day your brother/sister was diagnosed with their illness?

12. What has your family/whanau/doctors done that has been helpful for you?
   a. What have your friends done that has been helpful for you?
   b. What else would be helpful for you or other young people like you?

13. What should other young people know about what it’s like to be a young person with an unwell brother/sister?
   a. What advice would you give to another young person like you?

14. What should adults know about what it’s like to be a young person with an unwell brother/sister?

15. Has anyone else asked you questions like these before? Who?

16. I’ve just asked you heaps. Is there anything that you would like to ask me?

Thank you.
Appendix 35

Communication about Death described by Siblings

- Patience with the situation (7)
- Siblings want to be told (12)
- Not left in the dark/to fear the worse (6)
- Time to cope/prepare/seek comfort (4)
- Fear, worry (8)
- Negativity (2)
- Siblings do not want to talk about it (9)
- Pity, sympathy (3)
- Loss of normality (2)
Appendix 36

Key Results: Conceptual Model
References


Perceptions of Life and Death in Paediatric Palliative Care


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Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


*American Journal of Hospice and Palliative Medicine, 18*(3), 161-169.


*Omega J Death Dying, 43*(25), 63-91.


Perceptions of Life and Death in Paediatric Palliative Care


Hoboken, NJ: John Wiley & Sons Inc.


Perceptions of Life and Death in Paediatric Palliative Care


HIV/AIDS Res Palliat Care, 2.


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Perceptions of Life and Death in Paediatric Palliative Care


Slaughter, V. (2009). Question about "Death Understanding and Fear of Death in Young Children". In E. Gaab (Ed.) (Email ed.). Auckland.


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working committee on psychosocial issues in pediatric oncology. *Medical and Pediatric Oncology, 33*(4), 395-398.


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