

2005

## **Paediatric palliative and supportive care: caring for life: the needs of children and families in Western Australia**

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Monterosso, L., Kristjanson, L. Phillips, M. & Rowell, S. (2005). Paediatric palliative and supportive care: caring for life: the needs of children and families in Western Australia. Perth, Australia: School of Nursing, Midwifery and Postgraduate Medicine, Edith Cowan University.

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# Paediatric Palliative and Supportive Care

Caring for Life: The needs of children  
and families in Western Australia



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2005

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Contributing Authors: Leanne Monterosso, Linda Kristjanson, Marianne Phillips, Sue Rowell, Martin Wilson

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Paediatric Palliative and Supportive Care

Caring for Life: The needs of children and families in Western Australia

ISBN 0-7298-0605-7

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# Preface

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The study reported here provides a unique and much needed contribution to the future planning of palliative care for Western Australia.

The aims of the study were:

- 1) to better understand the needs of families of children suffering from life threatening conditions in Western Australia, and
- 2) identify the extent of service provision currently available for these families.

Results from this study provide an evidence base for the development of a statewide paediatric palliative care service.

The team undertaking this study involved a balanced blend of researchers, clinicians, consumers and community representatives with knowledge and expertise in issues related to care of children. The collaborative efforts of Edith Cowan University, the Children's Hospice Association (Inc), and Princess Margaret Hospital for Children have been especially helpful in ensuring a comprehensive examination of the issues was achieved.

Several important factors were considered during study design. There is a growing awareness of the need for co-ordinated and comprehensive palliative and supportive care for children who are chronically ill or have life-limiting illnesses and their families. The needs of this population are unique and require special consideration to enable the delivery of interdisciplinary care that aims to relieve suffering and improve quality of life. Although the needs of children who suffer either from a life threatening or chronic disability and/or illness and their families were thought to be significant, there was little evidence to verify the extent of this need in Western Australia.

An additional impetus for this study was the Children's Hospice Association (Inc) who had been actively raising funds and gathering support for the construction of a hospice in the Perth metropolitan area that would provide respite and end-of-life care for children and their families. The Children's Hospice Association generously provided in kind and financial support to ensure that this needs assessment could be undertaken to better inform future care for children with life-threatening and progressive illnesses.

This report presents the study findings from the perspective of families, as well as service providers. The results provide an extremely helpful set of recommendations for future palliative care planning and will form an important component of the overall health care review currently underway in Western Australia.

The team should be commended for this excellent report. The next steps will be to ensure that the palliative care and broader health care community work collaboratively to ensure that the recommendations arising from this study are realised.



Clive Deverell  
President, Palliative Care Western Australia

## RESEARCH TEAM

**Dr Leanne Monterosso:** Bluey Day Senior Research Fellow, School of Nursing, Midwifery & Postgraduate Medicine, Edith Cowan University; Senior Research Fellow, Princess Margaret Hospital for Children; Board Member Children's Hospice Association (Inc).

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**Dr Jane Valentine:** Consultant Paediatrician and Head Rehabilitation Medicine, Women's & Children's Health Service.

**Professor Kate White:** Professor of Nursing Research, University of Sydney.

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## ACKNOWLEDGEMENTS

The study was generously funded by the Children's Hospice Association (Inc), the Department of Health and Ageing, Edith Cowan University, the NHMRC, and the Western Australian Department of Health.

The contributions of a number of people made this study possible. Firstly, the input of health professionals committed to improvement in palliative care for children who participated in this study is gratefully acknowledged. Valuable input was also provided by the Paediatric Palliative Care Team at Princess Margaret Hospital. Members of this team include Ms Sue Rowell, Ms Anne Bourke, Professor Linda Kristjanson, Dr Leanne Monterosso, Mr Glyn Palmer, and Dr Marianne Phillips.

A special acknowledgement and thank you are extended to the following members of the Children's Hospice Association (Inc) whose patient commitment to this project and insightful input throughout the study were essential: Mrs Marjorie Bird, Mr David Bradshaw, Mrs Janet Bradshaw, Ms Cathrin Cassarchis, Canon Les Goode, The Honourable Des Heenan, Ms Rosemary Macpherson, His Honour George Sadlier, Mrs Sue Terry, Ms Jacky Vigurs, and Mr Martin Watson. These individuals provided the passion and were the driving force behind the study.

The study was supported by the following research assistants who worked professionally and tirelessly on the project: Ms Sky Dawson, Mrs Wilma Gill, Ms Elisa Pepall, Ms Rebecca Osseiran-Moisson, Mrs Toni Lampard, and Ms Karen Rooksby.

Finally, warmest gratitude is extended to the families who participated in this study. The willingness of the families involved in this project to share their experiences and offer their knowledge has resulted in a report that captures the challenges, complexity and magnitude of this important area of care. We dedicate this report to them.



# Executive Summary

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## BACKGROUND

Palliative care is the relief of symptoms, regardless of their impact on the underlying disease process. The philosophical underpinning of current international paediatric palliative and supportive care models is that palliative and supportive care should be offered to all children with life threatening or chronic illnesses/disabilities with complex care needs. This approach allows the integration of cure-directed treatment and palliative care, allowing children to benefit from both philosophies of care.

In Australia, there is increasing recognition of the need for the development of appropriate paediatric palliative care services, especially in Western Australia where supportive care services for children with life-limiting conditions are significantly underdeveloped.

The needs of children with life threatening conditions and their families are unique and require special consideration to enable the appropriate delivery of multidisciplinary care that aims to relieve suffering and improve quality of life. Although traditionally skills and knowledge base were developed for end-of-life care for adults, palliative care for children with life-threatening illnesses may be combined with curative or disease-modifying therapy.

In addition, a child's progressive, life-threatening illness has a profound effect on all dimensions of family life<sup>1</sup>. Families are affected emotionally, psychologically, and financially as family structure and organisation become permanently altered. Only recently have the specific palliative care needs of children and their families been recognised<sup>2-4</sup>:

- Children are physiologically and pharmacodynamically different to adults<sup>5-7</sup>.
- Children who require palliative care represent a smaller and more varied population in terms of the range of diagnoses encountered<sup>8</sup>.
- The treatment of childhood diseases incorporates tremendous variation in the state of readiness for transition to an exclusively palliative approach<sup>8</sup>.
- Aggressive attempts to prolong life are more likely in the paediatric setting<sup>9, 10</sup>.
- Access to key components of the palliative care model (i.e. supportive care that seeks to provide symptom control due to disease or treatment) is often required before a child begins palliation<sup>11</sup>.
- Developmental factors influence the child's understanding of illness and death, their ability to communicate and participate in decision-making, as well as their response to pain<sup>8</sup>.
- Paediatricians often develop longstanding relationships with children and their families and are less likely to hand over care<sup>10</sup>.
- In paediatric cancer, provision of palliative care is often of short duration<sup>10</sup> and traditional hospital care is not necessarily the most appropriate model for palliative care provision as most families of children with cancer will opt for home care if given the opportunity<sup>12</sup>.
- Grief is often more prolonged following the loss of a child<sup>13</sup>.

Current models of paediatric palliative care in Australia include hospital care services, free-standing hospices, home care programs, and residential care services. It cannot be assumed that models of palliative care that exist elsewhere in Australia are necessarily transferable without some modification for paediatric palliative and supportive care in Western Australia, given the diversity in geography, population distribution, illness profile, and provision of tertiary paediatric services. The notable lack of evidence to guide the development of Western Australian paediatric palliative and supportive care services provided justification for this study.

## OBJECTIVES

- To identify the palliative and supportive care needs of families of children with life threatening conditions.
  - To identify the palliative and supportive care services currently available to children with life threatening conditions and their families.
  - To examine how the palliative and supportive care needs of families of children with life threatening conditions are currently met.
  - To determine the extent to which the palliative and supportive care needs of families are met in hospital and community settings.
  - To determine the barriers and facilitating factors associated with the palliative and supportive care as perceived by parents and service providers.
- The term "parents" was used to represent all primary carers who participated in the study.

# METHODOLOGY

This two-phase study used both quantitative and qualitative methods.

**Phase I** comprised face-to-face or telephone interviews with 134 parents to administer a series of questionnaires to determine:

- The demographic profile of parents and children, including children's medical diagnoses and treatments.
- Children's abilities to perform essential daily functional skills.
- The needs of parents and siblings.
- Parents' education and support needs.
- Service and educational resource utilisation by children and parents in hospital and community settings.
- The level of anxiety and depression in parents.

Parents were stratified into two cohorts: non oncology and oncology. Stratification was undertaken because the majority of parents in the non oncology cohort had living children whilst the majority of the oncology cohort were bereaved and also involved in a national paediatric oncology palliative care needs study.

**Phase II** comprised in-depth interviews with 38 families to further explore the following major issues identified in Phase I:

- The concepts of palliative and supportive care.
- The need for family respite.
- Potential use of a children's hospice facility.
- Issues related to care of a sick child including the emotional and financial impact.

Semi-structured interviews were also undertaken with 20 service providers to determine:

- The extent of services provided.
- Client eligibility criteria.
- Waiting times.
- Types of services offered.
- Barriers and facilitating factors to service provision.

## KEY STUDY FINDINGS

1. Children with life-threatening and/or progressive illnesses prefer to remain at home for care whenever possible.
2. Many families are significantly affected physically, emotionally, mentally and financially.
3. Parents need ongoing multidisciplinary support from PMH throughout the trajectory of their child's illness.
4. Parents require specific assistance regarding the provision of care, including aids and equipment, appropriate nutrition and pain management for their sick children.
5. Home visits by health professionals are required by families of children requiring palliative care, especially to discuss management of nutrition and pain.
6. Professional carers providing in-home and residential respite care must be skilled in the care of such children.
7. Parents require clear, straightforward information about their child's condition, treatment and long term outcome.
8. Parents require education and practical assistance with caring for their other children.
9. Siblings of sick children have specific needs and are sometimes burdened with the care of their brother/sister.
10. Parents use and require access to a wide range of community education and resources.
11. Families of children who require end-of-life care prefer that care be provided in the home.
12. Families of children with chronic life-threatening illnesses/or disabilities require access to both in-home and residential respite care.
13. There is a need to improve current levels of in-home and residential respite care services.
14. Professional carers providing end-of-life-home care require specific paediatric knowledge and experience, particularly regarding medication dosages and administration.
15. Some parents of children with non-oncology conditions would use a dedicated children's respite centre.
16. Improved coordination between community-based disability services with service providers and families is required. There is a need for increased leadership to organise inter-agency collaboration, and for a case management approach for families.
17. The eligibility criteria for accessing support (e.g. respite, aids and equipment, allied health care, home care) are narrow and inconsistent.
18. There are a number of access and travel issues related to inadequate parking, limited public transport and ACROD bays at PMH and in the community.
19. There is a lack of recognition of the caring role, with many families feeling isolated and "battling on".

# CORE ELEMENTS IDENTIFIED FOR CONSIDERATION IN THE FUTURE DEVELOPMENT OF AN INTEGRATED PALLIATIVE AND SUPPORTIVE CARE SERVICE IN WESTERN AUSTRALIA

Results from this study have led to the identification of a model of care for a statewide paediatric palliative and supportive care service that is based upon two key principles:

- ❖ **Care must be community based**, linked and integrated with Princess Margaret Hospital in collaboration with other community services such as Disability Services Commission, Silver Chain and Lady Lawley Cottage.
- ❖ **Care must be coordinated** by a full multidisciplinary team in consultation with the children and their families.

The model must incorporate the following core elements:

1. Simple and accessible home-based care for all families of Western Australia.
2. Care that is individualised and responsive to parents' needs.
3. Care that is coordinated by a full multidisciplinary team.
4. More inclusive criteria for access to support services.
5. Access to flexible and responsive respite support.
6. Plans for long term care support.
7. Caters for end-of-life care.
8. Specific designated respite beds.
9. Need for specialised respite services for children with non-oncology diseases (home and special facilities).
10. Coordination between existing community-based disability services (in terms of palliative and supportive care for children), service providers and families (i.e. a need for broader criteria to accommodate the needs of children and their families, a need for increased leadership to organise inter-agency collaboration, and a need for a case management approach by families).

Empirical findings from this study provide specific guidelines for the broad delivery of palliative and supportive care for children suffering from life threatening or chronic illnesses/disabilities with complex care needs. Appropriate infrastructure support is required to facilitate the provision of quality and effective supportive and palliative care through partnerships between sick children, their families and health professionals.

# Introduction

Palliative care has evolved to meet the care needs of individuals who are seriously ill and dying and has largely focused on the needs of the adult population. More recently there has been an increased awareness of the need for co-ordinated and comprehensive palliative and supportive care for children with life-limiting illnesses and their families. The care required by these children may incorporate the principles of adult palliative care; however, the needs of chronically ill or dying children and their families are unique and require special consideration. The report presented here examines the specific needs of children.

The **two overall aims** of the study were:

- ❖ **to provide a broad and detailed description of the palliative and supportive care needs of Western Australian children and their families, and**
- ❖ **to identify the extent of service provision currently available for these families.**

## BACKGROUND LITERATURE

The focus of paediatric care has traditionally been limited to investigation, diagnosis, treatment and cure. This model of care has led to a dramatic change in the way children with life-limiting conditions (particularly those with cancer) receive care. Over the past two decades, advances in medical science and technology have been rapid and contributed to ever increasing survival rates for children with life-limiting illnesses. However, despite improved survival rates, there can be no assurance of cure and the imminence of death has been replaced by uncertain survival. Life-threatening illnesses that children may suffer from have been categorised as follows<sup>14</sup>:

- Conditions such as cancer for whom curative treatment is available but may fail,
- Conditions such as cystic fibrosis or HIV-1 infection requiring regular prolonged and intensive therapy that may provide a good quality of life, but may still result in premature death,
- Progressive conditions such as mucopolysaccharidoses where treatment is exclusively palliative from the time of diagnosis and may extend over many years, and
- Severe disabilities (often neurological) such as cerebral palsy or congenital anomalies that are neither progressive nor immediately life-threatening, but may lead to complications with a risk of premature death.

Many of these conditions are encountered only in paediatric practice.

**Definitions of Paediatric Palliative Care:** The growth of palliative medicine for adults has not been paralleled in paediatrics. Hence, there is a striking lack of evidence in the scientific literature relating to paediatric palliative care. Traditionally, palliative care has focused on the aging population and adults with a terminal illness, with a focus on cancer. In 2002 the World Health Organisation<sup>15</sup> issued the following paediatric-specific definition of palliative care:

“The active total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child’s physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children’s homes.”

This definition is more inclusive than traditional definitions and emphasises a palliative approach to care for children with a wide range of illnesses in a range of settings.

The definition provided by Palliative Care Australia<sup>16</sup> emphasises provision of care delivered, where possible, in the environment of the person’s choice, encompassing support to the patient’s family and friends. This definition also emphasises the provision of grief and bereavement support for the family and other carers during the life of the patient and continuing after his/her death.

Similarly, the American Academy of Pediatrics<sup>11</sup> (AAP) has suggested that traditional definitions of palliative care are too narrow and rigid and may prevent children who could benefit from palliative care services, but are not actively dying, from receiving such services. The AAP supports a model in which cure-directed treatment and palliative care are integrated, allowing the child to benefit from both philosophies of care.

A more useful definition that adopts these characteristics has been developed by the Royal College of Paediatrics and Child Health (UK) in conjunction with the Association for Children with Life-Threatening or Terminal Conditions and their Families:

“Palliative care for children and young adults with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement”<sup>17</sup>.

**Unique Palliative Care Needs of Children and Their Families:** The treatment of childhood diseases is notable because of the tremendous variation in the state of readiness for transition to an exclusively palliative approach<sup>8</sup>. As well, developmental factors influence a child's understanding of illness and death, his/her ability to communicate and participate in decision-making<sup>8</sup>. Access to key components of the palliative care model (ie supportive care that seeks to provide disease or treatment related symptom control) is often required before a child begins palliation<sup>11</sup>. Although the principles of palliative care from adult models can be applied to children with a life-limiting illness such as cancer, the specific needs of dying children and their families are unique and require special consideration<sup>2-4</sup>. A child's progressive, life-limiting illness has a profound effect on all dimensions of family life as families are affected emotionally, psychologically, and financially and family structure and organisation become permanently altered<sup>18</sup>. Paediatric health carers are becoming increasingly more aware that traditional hospital care is not necessarily the most appropriate model for palliative care provision, and that most families of children with cancer will opt for home care if given the opportunity<sup>12</sup>.

**Palliative Care Service Development for Children:** Worldwide, paediatric palliative and supportive care services have only recently developed<sup>8, 19</sup>. Seminal work by Frager<sup>8</sup> and Himelstein and colleagues<sup>20</sup> has recently confirmed that palliative care is appropriate for children with a wide range of conditions, even when cure remains a distinct possibility. The American Academy of Pediatrics<sup>21</sup> supports a model in which cure-directed treatment and palliative care are integrated, allowing the child to benefit from both philosophies of care. This model is strongly supported by the United Kingdom's Royal College of Paediatrics and Child Health in conjunction with the Association for Children with Life-Threatening or Terminal Conditions and their Families. Palliative and supportive care should be offered to all children with life threatening illnesses where cure is not an option, as well as to children with chronic illnesses/disabilities with complex care needs. These previously described models of paediatric palliative care, proposed and adopted by child health providers of the United States of America and the United Kingdom, provide a pathway for the delivery of paediatric palliative care. However, it cannot be assumed that the models developing in other parts of the world will necessarily be concordant with the Australian health care and cultural context.

**The Australian Context:** During the 1980s there were notable developments in the care of dying people in Australia. Since that time, palliative care has emerged as a specialised field in the health care system in Australia, and there has been significant growth in the number and type of palliative care services available. Unfortunately, this growth has largely focused on the needs of the adult population. Although there is an increasing awareness by health professionals of the need for comprehensive care for dying children and their families, there is a notable lack of evidence based literature to guide this newly emerging specialty of paediatric palliative care. There is a risk, therefore, that health providers and planners may feel pressured to respond to the needs of this unique population with adult models that are considered because they do not meet the specific needs of families of children dying from a terminal illness.

In Australia, development of palliative care services for children is in its infancy. The majority of families of children with life-limiting conditions choose to care for their children at home. However, caring for a chronically sick or dying child at home is an enormous and complex task. Depending upon the child's condition, families can be faced with long-term care regimens that can be complex and isolating. Limited time may be available to deal with day-to-day needs of healthier siblings, or to socialise with family and friends. Family carers often require a break from the constant pressures of caring on long term basis for the life-limited child and respite care may enhance the balance of family life and help maintain the viability of family care arrangements. However, families must be secure in the capabilities of the carers with whom they entrust the care of their child, as concern about the quality of care their child receives in families' absence can mitigate the benefits of any respite services offered to families. As well, circumstances of families caring for a child with a chronic condition may change so that access to respite services cannot always be planned well in advance. Some families will choose to care for their child in their own home during the final stage of their illness, often with the support of a professional team during this time, yet may be reluctant to spend this time in a hospital setting.

Although organisations exist in Western Australia that provide care for chronically sick and disabled children with life-limiting illnesses, no single organisation provides the comprehensive care needed by these children and their families. Members of the WA Children's Hospice Association (Inc), as well as some health professionals and community organisations involved in the care of these children and their families, believe that a children's hospice may be required. However, there is considerable debate as to whether funds would be better spent by improving home care services, offering respite for both children and their carers, or by providing a free-standing institution.

There are currently two children's hospice facilities in Victoria and New South Wales (Very Special Kids and Bear Cottage) and a children's hospice is under construction in Queensland. Development of these facilities was based on perceived family needs rather than empirically derived needs of the target population. To date, no formal evaluations of these services have been undertaken and whilst anecdotal reports indicate that these facilities are extremely helpful to many families, a population based assessment of needs of children with life-threatening and progressive illnesses who might benefit from these types of services is needed. Reports from key informants in these settings indicate that the development of these services did not involve collaboration with paediatric tertiary service providers. This issue has since been resolved and is recommended as an important strategy for others in planning similar types of services.

Some states provide paediatric pain and palliative care services, and/or dedicated paediatric palliative care consultants and teams. Evaluations of these models of care suggest that there may be elements of these services that would be helpful in Western Australia. Important lessons can be learned from these states regarding the infrastructure required for the development of supportive and palliative care services in Western Australia in conjunction with the population based needs assessment reported here. However, given the diversity in geography, population distribution, the disparity of support services and the existence of a sole tertiary paediatric referral centre, these types of facilities cannot be assumed to be appropriate for paediatric palliative and supportive care in WA. Therefore, an empirical approach to examining this issue within the context of WA was warranted.

This study addressed this knowledge deficit by determining the palliative and supportive care needs of families of children who have life-limiting conditions, how and where these needs were met, as well as the perceived barriers to service provision.

## **SPECIFIC STUDY AIMS**

1. What are the palliative and supportive care needs of families of children with life threatening conditions?
2. What palliative and supportive care services are currently available to children with life threatening conditions and their families?
3. How are the palliative and supportive care needs of families of children with life threatening conditions met?
4. To what extent are the supportive care and palliative care needs of families met in the hospital and community settings?
5. What are the perceived barriers and facilitating factors associated with the supportive care and palliative care as perceived by parents and service providers?

## **INNOVATION**

The striking feature of this important paediatric study was the level of inquiry undertaken in collaboration with academic staff, health professionals, and community agencies. The broad scope of the study was demonstrated by the age range of children (0 - 19 years) and families approached, the inclusive range of life-limiting conditions and chronic disabilities/illnesses, the representative sampling of families (metropolitan, regional and rural), and the comprehensive views and comments that were sought from families, health professionals, and community agencies<sup>22</sup>. As well, a creative mix of quantitative and qualitative methodologies was used to expand the scope and enhance the analytical power of the study<sup>23</sup>. This approach was supported by previous research with this population, that has shown the importance of asking families about their needs using a combination of simple quantitative questioning techniques as well as qualitative interviews to prompt further depth and detail regarding care needs.

## STUDY DESIGN AND METHOD

A prospective, two-phase descriptive study using a combination of quantitative and qualitative methodologies was used. The study was undertaken between February 2003 and March 2005.

## ETHICAL CONSIDERATIONS

Ethical approval to conduct this study was obtained from Edith Cowan University, Women's and Children's Health Service of Western Australia, South Metropolitan Health Service, Fremantle Hospital and Health Service, Confidentiality of Health Information Committee (CHIC), the Cerebral Palsy Association, and the Disability Services Commission.

## DEFINITIONS

The following terms have been defined and used throughout this study and report:

**Respite Care:** Supportive services for children with life-limiting conditions and their families. These services are provided by appropriately trained carers and include in-home care, day care, residential care, and end-of-life care.

**In-home care:** Services that are delivered by appropriately trained carers in the child's own home.

**Residential care:** Services that are delivered by appropriately trained carers in a designated children's care setting. This service also provides day care services for planned and emergency specialised childcare.

**Children's Hospice:** A "home away from home" for children with life-limiting conditions and their families that offers continuity of care, support and respite into adulthood and/or for the duration of life, that includes ongoing bereavement support following the death of the child.

# Phase I

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This phase comprised face-to-face or telephone interviews with parents to administer a series of six questionnaires to determine:

- A demographic profile of parents and children including children's medical diagnosis and treatments.
- Children's performance with essential daily functional skills.
- Parent and sibling needs.
- Parent education and support needs.
- Service and educational resource utilisation in both hospital and community settings.
- The level of anxiety and depression in parents.

## INCLUSION CRITERIA

Parents of children who suffered from a condition in any one of the following disease categories were eligible for inclusion in this study. Categories 1-4 comprise life threatening conditions originally devised by Goldman<sup>14</sup>. For the purpose of this study, an additional category (see 5) was added to include children with chronic illnesses/disabilities that had complex care needs, in keeping with current international paediatric palliative and supportive care models that suggest palliative and supportive care should be offered to children with life threatening illnesses or chronic illnesses/disabilities.

1. Conditions such as cancer for which curative treatment is available but may fail.
2. Conditions such as cystic fibrosis or HIV-1 infection requiring regular prolonged and intensive therapy that may provide a good quality of life, but may result in premature death.
3. Progressive conditions such as mucopolysaccharidoses where treatment is exclusively palliative from the time of diagnosis and may extend over many years.
4. Severe disabilities (often neurological) such as cerebral palsy or congenital anomalies that are neither progressive nor immediately life-threatening, but may lead to complications with a risk of premature death.
5. Other conditions, where patients have complex care needs (e.g. autism, intractable bowel disease, Crohn's disease, glutaric aciduria, cranio-facial malformation, endocrine disorders) or are receiving ongoing curative treatment but are not considered terminal.

Many of these conditions are only encountered in the paediatric setting.

## TARGET POPULATION

The population for this study included children with life-limiting conditions, and children with chronic disabilities or illnesses with complex care needs. It was not possible to determine the number of potential parents for this study as diagnostic information is not readily available in this state. In a UK study, Nash<sup>16</sup> estimated that 1:1000 children aged between 0-16 years will have a life-limiting illness, and of them, 25% will use palliative and supportive care services. According to the Australian Bureau of Statistics figures for 1999<sup>24</sup>, there were 480,200 children and adolescents aged between 0 - 17 years in WA. Based on these figures, use of Nash's<sup>16</sup> equation showed there were potentially 480 children with a life-limiting illness in WA at the time of study. Of these, 120 families were likely to use palliative and supportive care services.

## SAMPLE

Four hundred and ninety seven families were identified as eligible for inclusion in this study. Of these, 385 families were identified by staff (consultants, nurses, social workers, physiotherapists) at PMH, and 112 families through media advertisements. This figure closely matched the estimated number of potential parents using Nash's<sup>25</sup> formula. Despite ethical approval being granted from the PMH Committee for the Conduct of Ethical Research to approach these families through their child's treating consultants, consultants agreed for only 145 of the 385 families identified to be approached. As a result, a large media campaign was conducted to augment recruitment. Two hundred and fifty seven families (145 from PMH, 112 from responses to media advertisements) were approached for consent to participate in Phase I of the study. Of these, 138 parents consented to participate (54% response rate), of whom 134 were interviewed (97%).



## STUDY COHORTS

Parents were stratified into one of two cohorts: **non-oncology** that included parents of children with, or who had died from, a life threatening illness and **oncology** that included parents of children with, or who had died from cancer. Stratification was undertaken because the majority of parents in the **non-oncology** cohort had living children (i.e. 110 of 114 parents), whereas the majority of parents in the **oncology** cohort were bereaved (i.e. 19 of 20 parents). As well, parents in the **oncology** cohort were also involved in a national paediatric oncology palliative care study.

## RECRUITMENT PROCESS FOR PHASE I

According to the requirements of the PMH Ethics Committee, each parent was initially sent a letter of invitation (signed by the head of department if recruited through PMH, or, signed by the lead investigator if recruited through the media or community service agencies), a tick-box form and reply paid envelope. If parents chose to participate, they were advised to complete the tick-box form indicating their willingness to be sent an information sheet about the study and a consent form. Upon receipt of the signed consent form, the research assistant contacted each parent by telephone and arranged an appointment to conduct the Phase I interview either face-to-face or by telephone. At the completion of the Phase I interview, parents were asked if they would be willing to participate in Phase II.

## QUESTIONNAIRES

### 1. Demographic

The demographic questionnaire captured disease-related information and demographic data for children such as gender, age and clinical data consisting of type of diagnosis, age at diagnosis, treatment regimens, and the approximate date of transition from curative to palliative focus of care and death details if appropriate. In addition, demographic data about parents such as age, education and work details, and details about other children were collected.

### 2. Service and Educational Resource Utilisation (SERU)

This survey was originally developed by Pedersen and colleagues<sup>15</sup> for use in families of children with cancer in the Queensland population. The purpose of the SERU is to explore the access and/or use of services and educational resources available from community service agencies and/or local regional health centres. The SERU was amended to reflect the available community service agencies and/or local regional health centres in Western Australia. The SERU comprised seven sections and included yes/no, Likert-type and open ended questions as follows:

- Section 1: Services provided at PMH, community services and agencies, use and preference of respite, and use of a Children's respite centre (n = 47).
- Section 2: questions about travel to PMH or other treatment centres (n = 11).
- Section 3: questions about the financial impact of caring for a child with a life threatening illness (n = 7).
- Section 4: questions about use of educational and other resources at PMH (n = 15).
- Section 5: additional demographic questions about the child and family not included in the demographic questionnaire (n = 17).
- Section 6: comprised 14 items from the Hospital Anxiety and Depression Scale (see below for full description) as well as 2 questions about whether the care-giving role caused isolation and communication difficulties with family, friends and members of the general community.
- Section 7: questions about specific carer needs related to services and education (n = 13).

### 3. The Hospital Anxiety and Depression Scale (HADS)

The HADS<sup>26</sup> is a widely published, easy to use, validated and reliable tool to assess levels of psychological symptoms amongst a sample. The scoring system divides the total scores into four categories: normal (scores 0-7), mild (scores 8-10) and moderate (scores 11-14) to severe (scores 15-21) anxiety or depression. Although the title may suggest its use may be limited to patients in hospital, it has been shown to be a concise and useful instrument for other populations such as the parents in this study<sup>26</sup>. Previous Cronbach's alpha reliability coefficients of 0.78 for anxiety and 0.86 for depression have been reported for this instrument<sup>26</sup>.

In this study, the overall internal consistency for all scales for the oncology cohort was 0.80 for anxiety and 0.87 for depression; and was 0.80 for anxiety and 0.79 for depression for the non-oncology cohort. All scales were considered to be reliable.

#### 4. WeeFIM II

The WeeFIM II<sup>27</sup> is a widely used, reliable and valid tool that measures children's functional ability with everyday functioning. The WeeFIM II is an 18-item (with 8-14 levels per item), ordinal scale instrument that measures a child's consistent performance in essential daily functional skills according to the following three domains:

**Self-care:** eating, grooming, bathing, dressing upper and lower body, toileting, bladder and bowel management

**Mobility/Transfers:** chair/wheelchair, toilet, tub/shower, locomotion (walk/wheelchair) and stairs

**Cognitive:** comprehension, expression, social interaction, problem solving, memory

For each item in each domain, there were three possible scores: 1 = help required, 2 = supervision required, and 3 = no help or supervision required. The total score for each domain was calculated, and divided by the number of items.

Previous internal consistency scores (Cronbach's alpha) for all three domains have been reported between 0.85 - 1.00<sup>27</sup>. For this study, the internal consistency of the WeeFIM II for the oncology cohort was 0.86 for the self-care domain, 0.96 for the mobility domain, and 0.95 for the cognitive domain as calculated by the Cronbach's Alpha coefficient. The internal consistency for the non-oncology cohort was 0.95 for the self-care domain, 0.86 for the mobility domain, and 0.94 for the cognitive domain. All three domains for both cohorts used in this study were considered reliable.

#### 5. Patient Carer Needs Survey (PCNS)

The PCNS is a 16 item instrument derived from the Home Caregiver Needs Survey<sup>28</sup>. The 14 items represent "Patient Carer Needs Survey". For each item, parents/carers were asked to respond to three separate Likert-type scales ranging from 0-4. These scales measured perceived importance of the need (0 = not at all important, to, 4 = extremely important), how well the need had been met (0=not a need to 4=completely met), and if they would have liked to learn more (0=not at all, to, 4=a great deal). The PCNS has previously demonstrated stability as measured by test-retest procedures achieving dimension coefficients of 0.85-0.97<sup>20</sup>. The internal consistency reliability of this scale was demonstrated by an overall Cronbach's alpha coefficient of 0.93.

Cronbach's alpha coefficients for the oncology cohort study ranged from 0.81 to 0.87, and 0.82 to 0.83 for the non-oncology cohort indicating a high degree of internal consistency. All three subscales for both populations were considered reliable.

#### 6. Family Inventory of Needs-Paediatric "Fin-Ped"

The FIN-PED is based on the 20-item Family of Inventory of Needs (FIN) developed by Kristjanson and colleagues for use in an adult population<sup>29</sup>. The FIN-PED was modified for the paediatric population and tested as a 52-item instrument in a Canadian paediatric cancer setting<sup>30</sup>. Following data analysis, a modified 17-item version of the FIN-PED was developed. The FIN-PED is a multi dimensional instrument structured to include 3 subscales, the first measuring the importance of care needs, the second measuring the extent to which needs are met, and the third measuring the need for further information. All subscales have achieved an estimated internal consistency of 0.94, and there is evidence of the instrument's stability over time<sup>30</sup>.

Members of the research team have tested the FIN-PED with mothers and fathers of children with cancer in the sole tertiary referral centre of WA<sup>31</sup>. The FIN-PED demonstrated stability over time as measured by test-retest procedures achieving intraclass correlations between 0.79 and 0.95. The internal consistency reliability of each need according to the degree of importance, whether the need had been met, and whether parents required further information regarding the need was determined by calculation of Cronbach's alpha coefficients. These ranged from 0.83 to 0.98 indicating a high degree of internal consistency. The FIN-PED has also been tested for reliability in a major paediatric tertiary referral centre in Queensland with non-metropolitan parents. Internal consistency ranged from 0.77 to 0.95 for all but one subscale (the need for clear and open and clear responses to questions) where internal consistency ranged from 0.51 for the degree of importance to 0.78 for the need for more information<sup>15</sup>.

For this study, the internal consistency across all subscales for the oncology cohort ranged from 0.77 to 0.99, and 0.64 to 0.96 for the non-oncology cohort indicating a high degree of internal consistency.

# NON-ONCOLOGY COHORT

110 non-bereaved parents and 4 bereaved parents of children with life threatening illnesses other than cancer were interviewed. Given the small number of bereaved parents in this cohort, the findings presented are for non-bereaved parents only (n = 110).

## DEMOGRAPHIC CHARACTERISTICS

### Children's Diagnosis

As shown below and in Figure 1, the majority of children suffered from a condition that met the criteria for Category 4.

1. Conditions such as cancer for which curative treatment may fail (**see Oncology cohort results in next section**).
2. Conditions (e.g. cystic fibrosis or HIV-1) requiring regular prolonged and intensive therapy that may provide a good quality of life, but may result in premature death (**n = 15; 14%**).
3. Progressive conditions (e.g. mucopolysaccharidoses) where treatment is exclusively palliative from the time of diagnosis and may extend over many years (**n = 14; 13%**).
4. Severe disabilities (often neurological) such as cerebral palsy or congenital anomalies that are neither progressive nor immediately life-threatening, but may lead to complications with a risk of premature death (**n = 64; 58%**).
5. Other conditions where patients have complex care needs (e.g. autism, severe diabetes, Crohn's disease) or are receiving ongoing curative treatment, but are not considered palliative (**n = 17; 16%**).

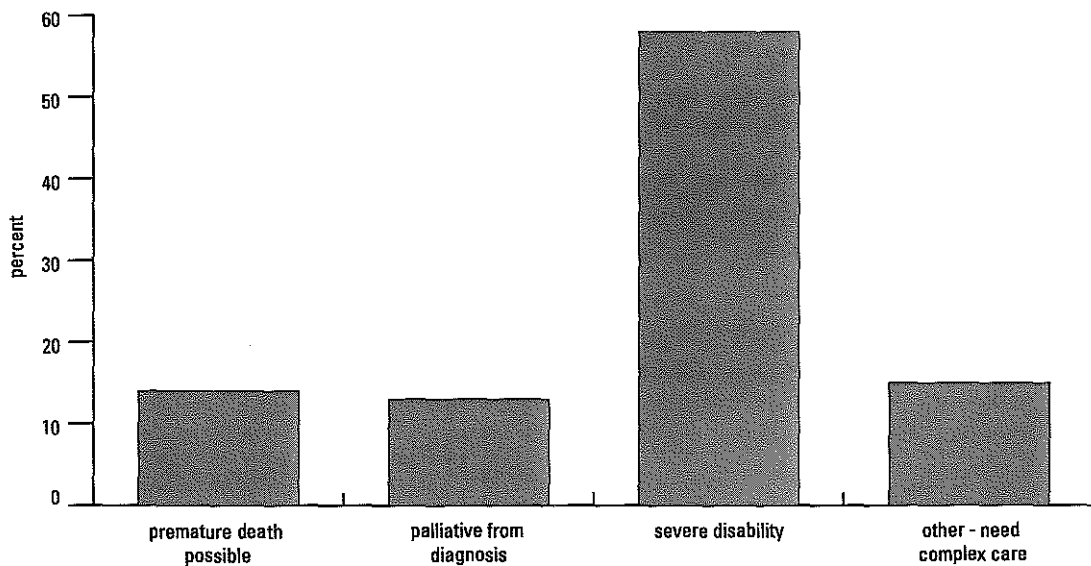
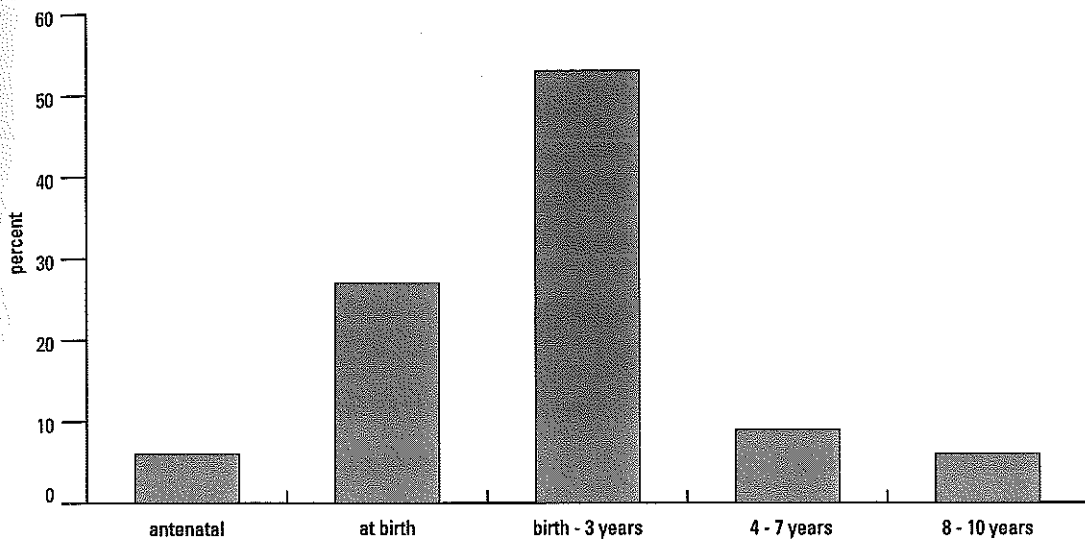


Figure 1. Diagnosis of children by disease category.

### Age of children at diagnosis

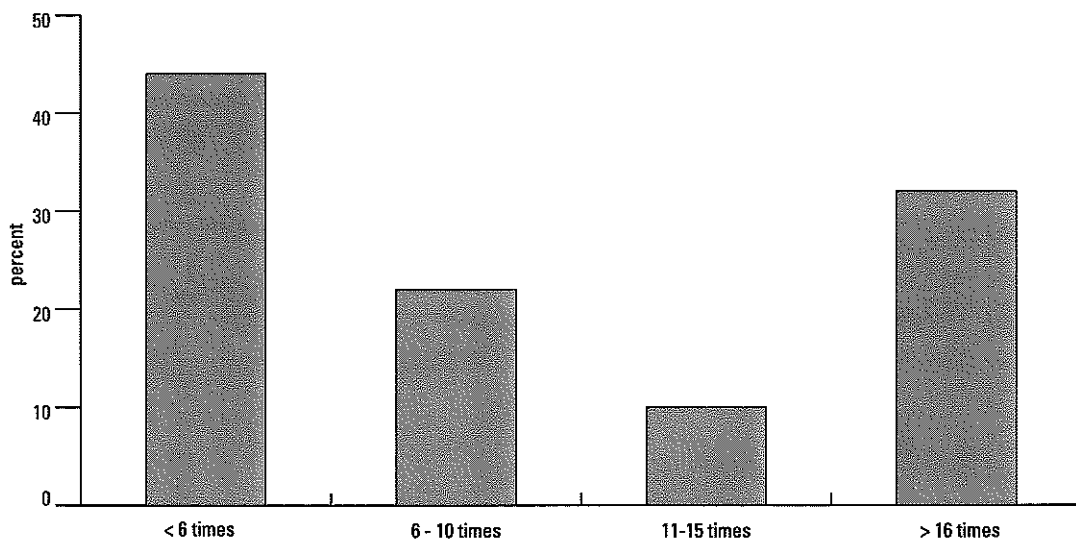
Figure 2 shows the majority of children were diagnosed between birth and 3 years of age (n=58, 53%).



**Figure 2. Age of children at diagnosis by age range in years.**

### Hospital Attendance

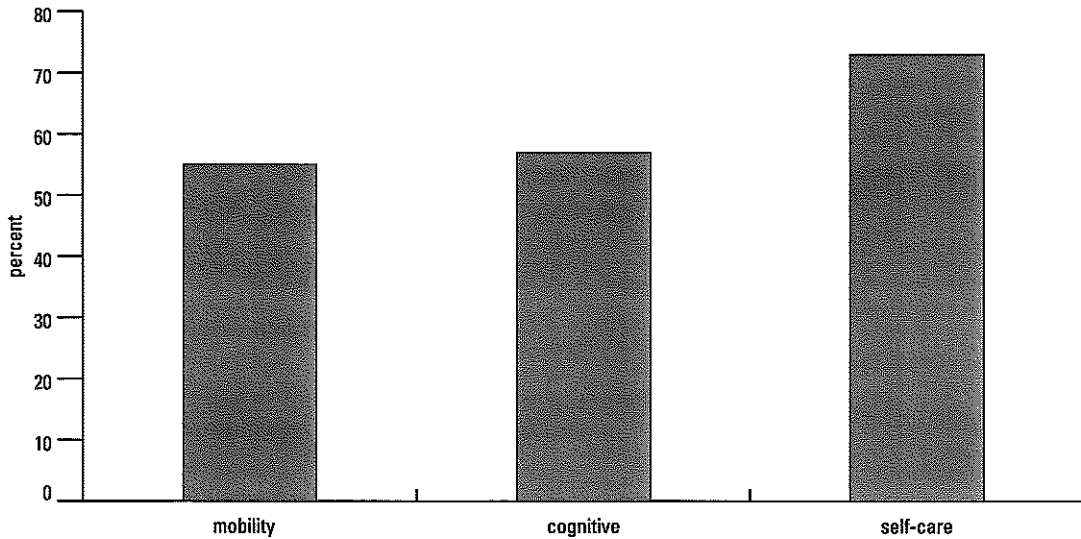
The majority of children received care from PMH (n=103, 94%) and over 30% (n = 33) of children were admitted to PMH on more than 16 occasions (Figure 3).



**Figure 3. Frequency of admission of children to PMH for treatment.**

## Children's functional ability with everyday activities

The Wee Fim II was used to measure children's functional ability with everyday activities. For the mobility domain, the mean score was 2.04 (SD = 0.75); for the cognitive domain the mean score was 1.92 (SD = 0.81); and for the self-care domain the mean score was 1.62 (SD = 0.67). Across all domains 58 (n=64) of children required some help or supervision (Figure 4). A significant proportion of children required assistance with mobility (n=60; 55%), cognitive tasks (n=63; 57%), and self-care (n = 80; 73%).



**Figure 4. Assistance required with daily functioning assessed by the Wee Fim II according to the mobility, cognitive and self-care domains.**

In the mobility domain, the most highly ranked problems occurred with:

- Coping with bath or shower transfers
- Wheelchairs
- Stairs

Eighty two percent (n=90) of the children walked, 16% (n=18) used a wheelchair and 2% (n=2) crawled.

In the cognitive task domain, the most highly ranked problems included:

- Problem solving
- Memory
- Comprehension

In the self-care domain, the most highly ranked problems included:

- Dressing the lower body
- Bathing and toileting
- Dressing the upper body

### Parents' demographic details

- Seventy four percent (n = 82) of parents resided in the metropolitan area, and 26% (n = 28) in rural areas.
- Most parents were aged between 31-40 years (n = 56; 51%), with 37% (n = 41) aged between 41-50 years (Figure 5).

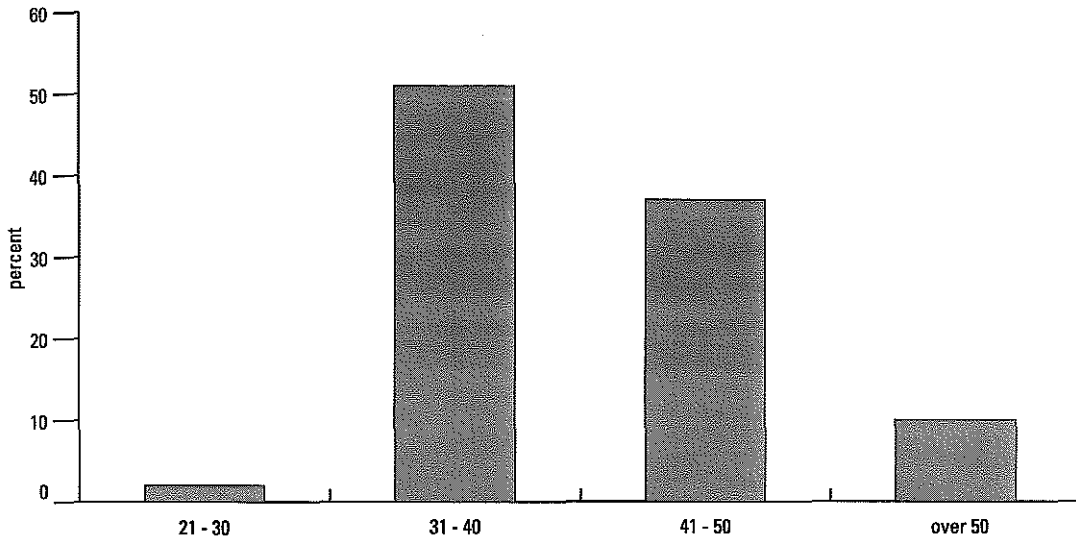


Figure 5. Age range of parents in years.

- 74% (n = 81) of parents were married or were living in a defacto relationship, and 25% (n = 28) were single parents
- 32% (n = 35) of parents had a bachelor's degree or higher, 25% (n = 28) had no tertiary qualification and 23% (n = 25) had a certificate/diploma
- 30%(n = 33) of parents worked full time
- 42% (n = 46) of parents were full time home carers
- 92% (n = 101) of children held a Health Care Card
- As shown in Figure 6, the majority of parents were mothers (76%, n = 82)
- Care was shared between mothers and fathers in 21% (n=23) of cases

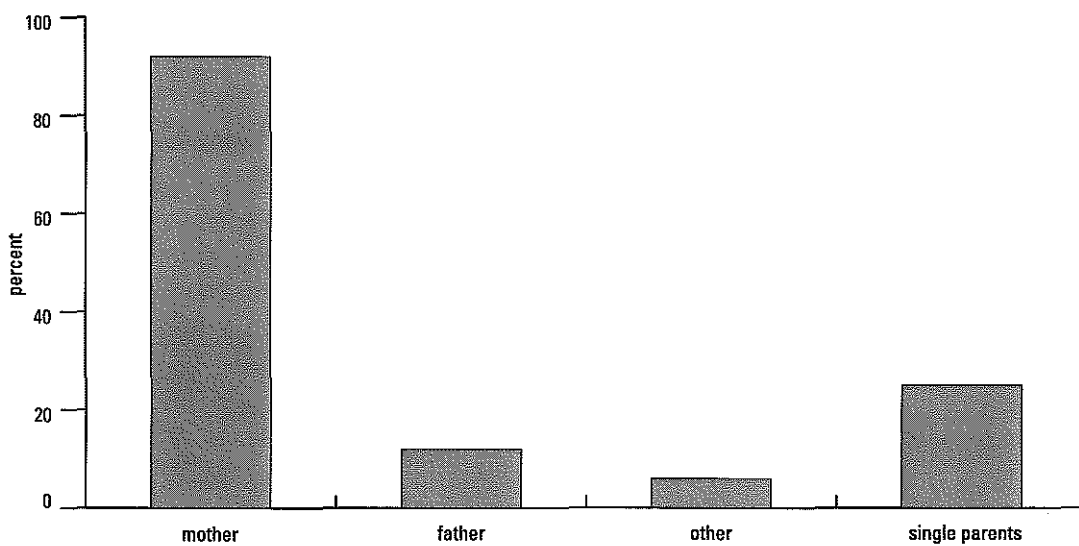
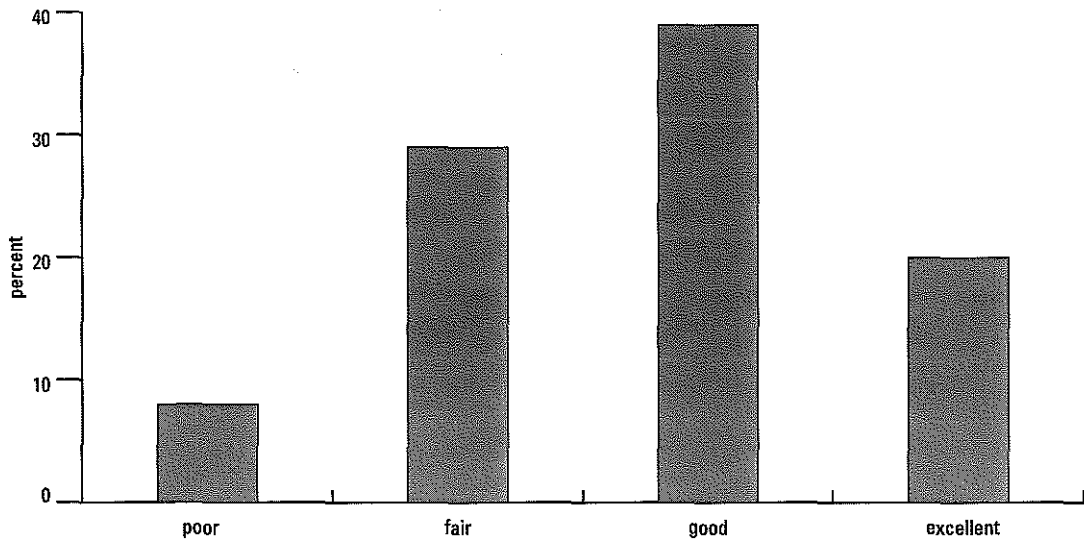


Figure 6. Carer status.

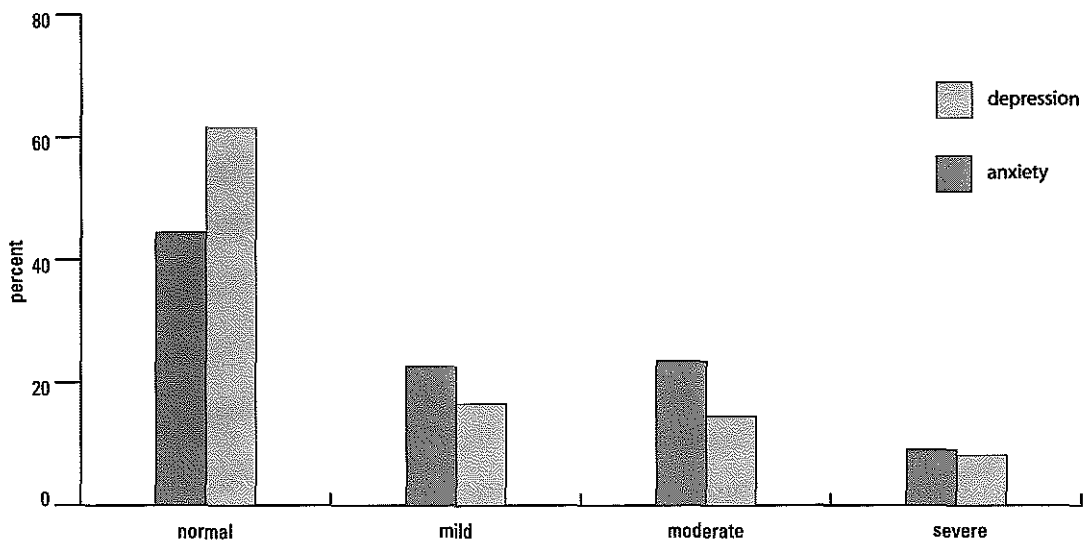
### Impact of child's condition on parents and family

As shown in Figure 7, 37% (n = 41) of parents reported their general health as either poor or fair, and 59% (n = 65) as either good or excellent.



**Figure 7. General health status of parents.**

As previously described, the Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression in the parents of this study at the time of interview. Thirty three percent (n = 36) of parents reported moderate to severe anxiety and 23% (n = 25) of parents reported moderate to severe depression (Figure 8).



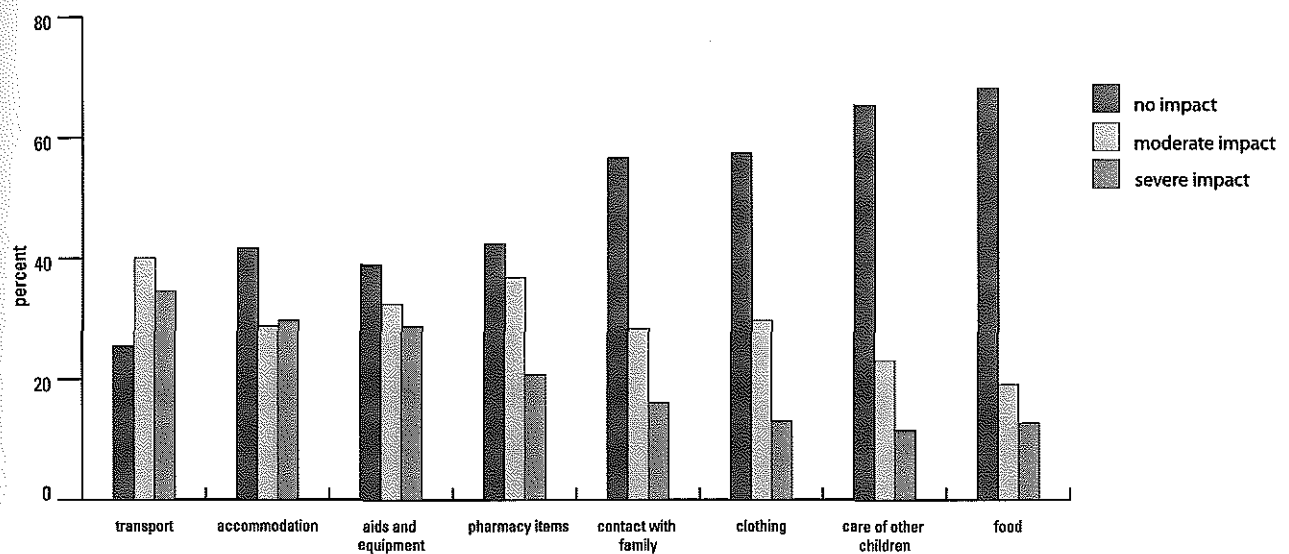
**Figure 8. Anxiety and depression in parents as measured by the HADS.**

A large proportion of parents (77%; n = 85) stated the care-giving role caused them to feel isolated from friends and family. The majority of parents (n = 96; 87%) also reported the care-giving role had affected their ability to go on family holidays or attend family social events. Qualitative data confirmed the above findings and demonstrated that many parents had not had a holiday since their child was born or diagnosed. Table 1 shows that overall, 86% (n=94) of parents reported a moderate to very high overall financial impact as a result of caring for their sick children.

**Table 1 Overall financial impact of caring for a sick child (N=110).**

Overall financial impact	n	%
None	4	3.6
Small	12	10.9
Moderate	29	26.4
High	33	30.0
Very high	32	29.1

Costs related to transport, accommodation, pharmacy items and aids and equipment accounted for the majority of the financial impact (Figure 9). Only 21% (n=23) of parents had access to transport benefits, and only 15% (n=16) had access to accommodation benefits.



**Figure 9. Costs contributing to overall financial impact of caring for a sick child.**

#### Travel to hospital and parking arrangements

- 93% (n = 102) of parents used a private car for transport to hospital or treatment centre
- 43% (n = 47) of parents who resided in metropolitan areas spent less than 30 minutes travelling to PMH and 49% (n = 54) of parents took between 1/2 hour to 1 hour. No participant spent more than 2 hours. For all parents/carers, the travelling distance was less than 100km (80% less than 50 km and 20% less than 100 km)
- 80% (n = 20) of parents who resided in rural areas travelled for less than 1 hour to reach PMH, 39% (n = 43) took between 1 to 2 hours and 25% (n = 28) over 4 hours. The travelling distance was between 50 and 199 km for 32% (n = 35) of parents and over 200km for 64% (n = 70) of these parents. 18% (n = 20) of parents residing in rural areas travelled to hospital by air
- 59% (n = 65) of parents experienced moderate to severe difficulty travelling to PMH
- Of the 89% of parents who travelled to PMH for their child's care, 77% (n = 75) stated that parking was an issue, 8% (n = 8) stated that travelling from home to PMH was a problem and 12% (n = 12) complained about waiting times to see health professionals

A large proportion of parents stated they found both travelling to, and parking at PMH difficult and this appeared to have an impact on their quality of life. The parents in this study were particularly affected because many children were not independently mobile and required assistance with mobility (e.g. wheelchairs).



### Travel to Community Services.

- 98% (n = 108) of parents used local health services.
- All parents living in metropolitan areas spent less than 1 hour travelling to these local services (65% less than 30 minutes, 35% less than 1 hour). For 89% the distance travelled was less than 50km.
- 97% (n = 27) of parents living in the rural area travelled less than 1 hour to reach these services, 79% less than 30minutes, 18% between 1/2 hour and 1 hour, and 4% between 1 and 2 hours. The distance was less than 50 km for 89% of rural families. No family travelled more than 200 km to reach local health services.
- 83% (n = 91) of all parents experienced minimal to no difficulty when attending local services.
- 60% (n = 66) of all parents received support from ACROD.
- 42% (n =45) of parents who travel to local health services commented about this issue. For 32%, travelling from home to local health services was a problem. It was generally difficult for 20% (n = 22) and parking was an issue for 16%.

### **KEY HEALTH PROFESSIONALS, SERVICES, AND RESOURCES AT PMH**

The Service and Educational Resource Utilisation (SERU) questionnaire was used to determine use of PMH services (including key health professionals).

Section 1 of the SERU questionnaire was used to explore the use of PMH services (including key health professionals). Parents were then asked how easy it was to access each professional/service, and how helpful these were using Likert-type scales ranging from 0 - 4 (0 = not at all, to, 4 = extremely). Results represent items rated as either 3 or 4 (Table 2).

**Table 2. Frequency of access, ease of access, use and helpfulness of key health professionals and services at PMH (N=103).**

PMH health professionals and services	Had access		Ease of access		Frequency of use		Helpfulness	
	n	%	n	%	n	%	n	%
Specialist doctors	100	97.1	54	54.0	97	97.0	69	71.1
Other health services (see Table 3)	63	61.2	49	77.8	61	96.8	53	86.9
Dietician	49	47.6	23	46.9	47	95.9	28	59.6
Physiotherapist	47	45.6	26	55.3	46	97.8	37	80.4
Liaison nurses	45	43.7	33	73.3	44	97.8	33	75.0
Occupational therapist	38	36.9	24	63.2	38	100.0	28	73.7
Social worker	38	36.9	22	57.9	36	94.7	23	63.9
Children's activity co-ordinator	34	33.0	27	79.4	33	97.1	26	78.8
Dentist	34	33.0	16	47.1	34	100.0	27	79.4
Psychologist	26	25.2	13	50.0	22	84.6	7	31.8
Pain team	13	12.6	11	84.6	13	100.0	10	76.9

**Table 3. Other services at PMH used by children and their parents.**

Audiology	Neurology clinic
Chaplain or Minister	Neuroscience
Diagnostic tests eg. cardio tests	Ophthalmologist
Early intervention team	Orthopaedic appliances
EEG	Orthopaedic clinic
Emergency (accident)	Orthotics
Emergency (for admission)	Pharmacy
Endocrinology	Physio for Botox injections/treatment
ENT (Ear nose throat)	Psychologist
Epilepsy dept. Ophthalmologist	Respiratory clinic
Eye Clinic	Respiratory medicine
Gastro-enterologists	Sleep study clinic
Genetic counselling	Speech Therapy
Hip surveillance clinic	Spinal clinic
Hydrotherapy pool	Stoma therapy
Immunoglobulin service/ immunology	School
The Kalparrin Centre*	Home visiting nurse
Medical supplies	

\* Help and support for families of children with special needs.

Key professionals and services most frequently used were: specialist doctors, other services and dieticians. Key professionals and services easiest to access were: the pain team, children's activity co-ordinators, and other services. The most helpful key professionals and services were: other services, physiotherapists, and dentists.

### Resources at PMH

Parents were asked to rank resources at PMH according to frequency of use and helpfulness (results shown reflect parents who ranked the resources as either very or extremely useful). The results are shown Table 4.

**Table 4. Frequency of use and helpfulness of resources at PMH (N=110).**

PMH resources	Frequency of use		Helpfulness	
	n	%	n	%
Specialised agencies (e.g. Cerebral Palsy Association, DSC)	92	89.3	74	80.4
General information from nurses on the ward	65	63.7	42	64.6
Internet sites about your child's condition and treatments	58	56.8	36	62.1
Written information sheets about your child's specific condition/ problem	55	54.5	29	51.8
Pamphlets about your child's specific condition/problem	52	51.0	26	51.0
Education by staff about how to care for your child at home	52	51.0	36	69.2
Information or advice from family and friends	48	47.1	18	37.5
Information from PMH liaison nurses	43	42.2	28	65.1
Support groups or programmes	34	34.7	22	64.7
Educational videos	19	18.8	8	42.1
Programmes/courses about your child's condition	17	16.7	13	76.5
Audio-visual material (e.g. television, audio-tapes, videos)	13	12.9	8	61.5
Practical aids for teaching (e.g. photos of child's programme)	12	11.8	7	58.3

The resources most frequently used were specialised agencies, general information from ward nurses, and internet sites about the child's condition and treatments.

The resources considered "most helpful" were specialised agencies, programs/courses about child's condition, and education by staff about how to care for the child at home.

## COMMUNITY SERVICES AND RESOURCES

Parents were asked to rank key community services and resources according to frequency of use and ease of access and helpfulness. Table 5 shows results for services and resources rated as either: very or extremely easy to access, and very or extremely helpful.

**Table 5. Frequency of access, ease of access, use and helpfulness of community resources (N=110).**

Community resources	Had access		Ease of access		Frequency of use		Helpfulness	
	n	%	n	%	n	%	n	%
Local general practitioner	92	83.7	60	65.2	91	98.9	67	73.6
Disability Services Commission	73	66.4	48	65.7	73	100.0	45	61.6
Other health services (see Table 6)	63	57.3	45	71.4	63	100.0	50	79.4
Complementary medicine practitioners	37	33.7	0	0.00	36	97.3	0	0.0
Local public hospital	36	32.7	23	63.9	35	97.2	24	68.6
Local paediatrician	35	31.8	21	60.0	34	97.1	32	94.1
Community support services (specify e.g. church)	35	31.8	31	88.6	34	97.1	29	85.3
Community health nurse	32	29.1	17	53.1	22	68.7	13	59.1
Cerebral Palsy Association	32	29.09	20	62.50	30	93.75	24	80.0
Private therapy	29	26.4	17	58.6	26	89.7	21	80.7
Silver Chain	26	23.6	14	53.8	25	96.1	18	72.0
Local public hospital with a paediatric facility	14	12.7	6	42.9	14	100.0	7	50.0
Local private hospital	8	7.3	7	87.5	6	75.0	4	66.7
Local private hospital with a paediatric facility	5	4.5	4	80.0	4	80.0	3	75.0

**Table 6. Other community resources used by children and their parents.**

Child Development Centre	Red Cross Respite
Chiropractor	Riding for the disabled
Dentist	Rocky Bay
DSC camp	Ronald McDonald House
Hydrotherapy	School Age Therapy Services (SATS)
The Kalparrin Centre*	School dentist
Lady Lawley Cottages	School nurse
Local cardiologist	School nurse
Massage	School psychologist
Neurological Council	Speech therapy
Occupational therapy	Spina Bifida Association
Perth Home Care	Therapy Focus
Physiotherapy	

\* Help and support for families of children with special needs.

The key services and resources most frequently used included the local GP, Disability Services Commission and other services. The key services and resources most easily accessed were the local GP, Disability Services Commission, and other services. The most helpful key services and resources were the local GP, other services, and Disability Services Commission.

## RESPITE AND SUPPORT

### Family support

The majority of parents relied on support from their immediate family. Table 7 shows that 64% (n=70) of parents relied on support from their partner.

**Table 7. Support from immediate family (N=110).**

Immediate family member	n	%
Partner (husband, wife or partner)	70	64
Other children	16	15
Combination	9	8

Table 8 shows that 56% (n = 51) of parents relied on support from their extended family, mainly grandparents (n=34; 31%).

**Table 8. Support from extended family (N=51).**

Extended family member	n	%
Grandparents	34	31
Parents' sibling	11	10
Combination	11	10
Neighbours	9	6
Others (ex partner, babysitter, other members of extended family)	6	5

### Respite

Government funded or private in-home care was used by 46% (n= 51) of families. As shown in Table 9, the three agencies most frequently used by families were i.dentity.wa (18%), Disability Services Commission (DSC - e.g. Getabout) (18%) and the Cerebral Palsy Association (16%). Of note, 12 (24%) families used a combination of agencies. 11 (22%) families did not specify the name of the agency used.

**Table 9. Agencies used for in-home respite (N=51)**

Agency	n
Combination of agencies used	12
Other (not specified)	11
i.d.entity.wa (formerly Catholic Care)	9
DSC (eg. Get About)	9
Cerebral Palsy Association (CPA)	8
Activ Foundation	6
Rocky Bay	3
Home and Community Care (HACC)	2
DSC Local Area Coordinators (eg. Home Care Pursuit)	2
Perth Home Care	2
Red Cross Respite	2
Sense	2
Silver Chain	2
Lady Lawley Cottage	1
Neurological Council	1
Babysitter	1
Southwest Family	1
YMCA	1
Private aid	1

Table 10 shows agencies used for residential respite care. Forty six percent of families used government funded or private respite out of home. The three most frequently used associations were i.d.entity.wa (n = 11, 24%), Lady Lawley Cottage (13%), DCS (11%), and Red Cross Respite (11%). 9% of families did not name the associations used, and 16% of families used combination of several associations.

**Table 10. Agencies used for residential respite care (N=45).**

Agency	n
i.d.entity.wa (formerly Catholic Care)	11
Combination of agencies used	7
Lady Lawley Cottage	6
DSC (e.g. Get About)	5
Red Cross Respite	5
CPA	4
Private aid	4
Other (not specified)	4
Rocky Bay	3
Activ Foundation	2
Host Family	2
Regional associations	2
LAC (e.g. Home Care Pursuit)	1
Post Options	1
Southwest Family	1
Wesley Mission	1
YMCA	1

Table 11 shows that 24% (n=11) of families used residential respite care on a weekly basis, and 24% (n=11) of families used respite at intervals of greater than one month. Residential care was used mainly overnight (n=25, 56%) or during daylight hours (n=23, 51%). 11 (24%) families used residential respite care for a number of different time periods.

**Table 11. Frequency and time of use for residential respite care (N = 45).**

	n
<b>Frequency of use</b>	
Daily	1
Weekly	11
Weekend	4
Fortnightly	4
Monthly	8
Period greater than one month	11
Occasionally	3
<b>Time preference</b>	
Day	23
Night (including evening)	25
Holidays	7
Weekend only	10
Combination of above	11

- 43% (n=47) of families reported experiencing a waiting period for accessing in-home and residential respite care services
- The mean waiting period was 10 months (SD = 9.76), with a range of 1.5 months to 3 years
- 40% (n=44) of families did not use either in-home or residential respite care services. Of these families, 25% would have preferred to use in-home care services, 23% would have preferred to use residential care, and 18% would have preferred to use respite provided by other family members
- Only 2% of families felt they did not need respite services
- Families who would choose to use residential care prefer the location to be within easy travel distance, and were prepared to travel a mean distance of 76 km (SD = 82.44), with a range of 2km to 200km
- If given the option, families prefer to use in-home respite services on a weekly or monthly basis

#### Respite centres

- 34% (n=17) of families who accessed respite services used either a dedicated respite centre (n=13; 26%), or family home (n=4; 7%)
- The age range (based on median scores) of children and adolescents cared for in paediatric specific respite centres (89%; n=45) ranged from 0 to 18 years
- The mean travel distance to centres was 45 km (SD = 78.32), range was 1 - 400 km

#### Children's respite centre concept

72 (79%) parents responded to a specific question regarding use of a dedicated children's respite centre if available. 51% (n=37) said they would use such a facility, and 49% (n=35) said they would not. Of the families who would use a dedicated Children's respite centre, use of the centre would be on a monthly or weekend basis (Table 12).

**Table 12. Projected use by parents of a dedicated children's respite centre according to frequency and time preference (N = 32).**

Agency	n
<b>Frequency of use</b>	
Daily	1
Weekly	4
Fortnight	3
Monthly	9
Period greater than one month	8
Occasionally	5
<b>Time preference</b>	
Night (including evening)	1
Holidays	1
Weekend only	2

#### Independent living program

- 46% (n = 42) of parents thought their sick children would not be able to live with them in future. Fourteen percent of parents were unsure if their children would continue to be able to live with them in future
- 59% (n=65) of parents believed their sick children would require future placement in an independent living program. Of these, 68% (n=75) had already explored this issue

## CARER NEEDS

The Patient Carer Needs Survey (PCNS) was used to determine the needs of parents. The PCNS comprised 14 items (i.e. needs). For each need, parents were asked to respond to three separate Likert-type scales ranging from 0-4. These scales measured the perceived importance of the need (0 = not at all important, to, 4 = extremely important), how well the need had been met (0 = not a need, to, 4 = completely met), and whether parents would have liked to learn more about the particular need (0 = not at all, to, 4 = a great deal). Results for items scored as either 3 or 4 are shown in Table 13.

**Table 13. Needs of parents (N=110).**

Patient carer needs	Important		How well met		Need more information	
	n	%	n	%	n	%
To know how to obtain equipment to help with my child's care (e.g. Kanga pump, orthotics, wheelchair).	57	54.3	25	23.8	20	20.0
To have home visits by health professionals as needed (e.g. for therapy or by the Visiting Nurse).	54	51.0	36	34.0	25	24.7
To know ways to maintain a normal lifestyle with my child.	52	50.0	42	40.4	36	34.9
To know ways to deal with difficult behaviour.	51	47.7	50	46.7	42	39.2
To know more about ways to help me care for my child.	50	46.0	50	46.0	39	36.1
To know about ways to provide my child with adequate nutrition.	48	44.4	33	30.8	28	26.2
To know what information to give my child (appropriate to his/her age).	46	43.0	38	35.5	32	31.1
To know how to help my child participate in activities with the able-bodied in the community.	46	42.2	49	44.9	37	33.9
Assistance in methods of medical management for my child (e.g. Kanga pumps, seizure management).	29	27.6	14	13.3	12	11.6
To know ways to overcome problems associated with use of a wheelchair.	24	24.5	25	25.5	19	19.8
Information about how to get my child to eat.	25	24.0	30	28.5	22	21.6
To know about ways to help keep my child comfortable.	23	22.0	16	15.4	12	11.5
Information about nutritional drinks for my child.	15	14.9	16	15.7	13	13.0
To know ways to help my child feel better about his/her appearance.	15	14.6	18	17.3	12	11.9

The highest rated carer needs were: to know how to obtain equipment to help with child's care, to have home visits by health professionals as needed, and to know ways to maintain a normal lifestyle with child.

Carer needs that were not well met were: to know ways to deal with difficult behaviour, to know more about ways to help care for child, and to know how to help child participate in activities with the able-bodied in the community.

The needs about which parents requested more information were: to know ways to deal with difficult behaviour, to know more about ways to help care for child, and to know ways to maintain a normal lifestyle with child.

## SERVICE AND EDUCATIONAL NEEDS

Section 7 of the SERU was used to explore the specific carer needs related to services and education. For each need, parents were asked to respond to three separate Likert-type scales ranging from 0-4. These scales measured the perceived importance of the need (0 = not at all important, to, 4 = extremely important), how well the need had been met (0 = not a need, to, 4 = completely met), and whether parents would have liked more information about the particular need (0 = not at all, to, 4 = a great deal). Results for items scored as either 3 or 4 are shown in Table 14.

**Table 14. Carer needs related to service and education needs (N=110).**

Carer service and educational needs	Importance		How well met		Need more information	
	n	%	n	%	n	%
To know about what financial assistance is available (e.g. Patient Assisted Travel Scheme (PATS))	68	61.8	75	68.2	58	53.2
To have access to more specific sources of information about my child's condition	58	52.7	51	46.4	42	38.9
To have practical help with my child at home	55	50.0	62	56.3	36	33.0
To have access to health care professionals' advice out of regular hours	48	43.6	45	40.9	28	26.2
To know about complementary medicines and treatments for my child (e.g. vitamins and herbal tonics)	42	38.2	50	45.4	32	29.4
To know about local health care resources while at home	40	36.4	45	40.9	30	27.8
To know more about the role of other medicines for my child (e.g. antibiotics)	28	25.4	28	25.4	14	13.0
To know more about managing travel and distance issues	15	13.8	21	19.3	16	15.0
To know about school/day care options for my other children	7	9.0	7	9.0	4	5.3
Help in administering medications to my child	8	7.3	6	5.4	2	1.8

The most important service and educational needs were: to know about what financial assistance is available, to have access to more specific sources of information about child's condition, and to have practical help with child at home.

The service and educational needs not as well met as expected by parents were: to know what financial assistance is available, to have practical help with child at home, and to have access to more specific sources of information about child's condition.

Parents needed more information about the needs: to know about what financial assistance is available, to have access to more specific sources of information about child's condition, and to have practical help with child at home.



## FAMILY NEEDS

The family Inventory of Needs – Paediatric (FIN-PED) was used to determine the needs of parents. The FIN-PED comprised 17 items (i.e. needs). For each need, parents were asked to respond to three separate Likert-type scales ranging from 0-4. These scales measured the perceived importance of the need (0 = not at all important, to, 4 = extremely important), how well the need had been met (0 = not a need to 4 = completely met), and whether parents would have liked to learn more about the particular need (0 = not at all, to, 4 = a great deal). Results for items scored as either 3 or 4 are shown in Table 15.

**Table 15. Family needs.**

Family needs	Important		How well met		Need more information	
	n	%	n	%	n	%
To feel that the health care professionals were sincere in caring about my child	103	93.6	22	20.0	16	15.1
To know I could ask questions any time	103	93.6	28	25.4	20	19.1
To be told when and why changes were being made in my child's treatment plans	97	90.6	19	17.8	16	15.4
To have explanations given in terms that were understandable to me	97	88.2	27	24.5	19	18.1
To have trust in the health-care system	96	87.3	56	50.9	36	34.3
To feel there was hope	90	81.8	56	50.9	28	27.7
To know to whom I should direct my questions	90	81.8	36	32.7	20	19.1
To be informed of changes to my child's condition	89	81.6	30	27.5	29	27.6
To know that healthcare professionals would offer me the opportunity to participate equally in my child's care	85	78.0	23	21.5	14	13.1
To know what treatment my child was receiving	83	76.8	8	7.4	10	9.5
To know what side effects the treatment can cause	76	69.7	42	38.9	38	35.5
To know the probable outcome of my child's illness	73	67.6	49	45.4	31	29.5
To know when to expect side effects to occur	68	62.4	68	62.4	49	47.6
To know how to handle the feelings of my other children	54	53.5	40	39.6	31	31.3
To know how to give information to my other children (appropriate to his/her age)	48	48.5	30	30.3	23	23.5
To know what information to give to my other children (appropriate to his /her age)	46	46.5	33	33.0	24	24.5
To have thorough information about how to care for my child at home	39	36.8	25	23.6	21	20.2

The highest rated family needs were: to feel that the health care professionals were sincere in caring about child, to know parents could ask questions any time, and to be told when and why changes were being made in child's treatment plans.

The family needs not as well met as expected were: to know when to expect side effects to occur, to feel there was hope and to have trust in the health-care system, and to know the probable outcome of child's illness.

Highest rated needs about which parents required more information were: to know when to expect side effects to occur, to know what side effects the treatment can cause, and to have trust in the health-care system.

## SUMMARY OF PHASE 1 FINDINGS FOR NON-ONCOLOGY COHORT

The majority of parents were caring for a child with a non-progressive neurological condition. Most children were diagnosed between birth and the age of 3 years and attended Princess Margaret Hospital (PMH) often, either as inpatients or outpatients. Many children required assistance with daily functioning (mobility, self care and cognitive skills). Most parents were aged between 31 and 50 years of age, and lived in the metropolitan area. Of these, a significant number were single parents. Most parents experienced a significant financial impact, and feel the burden of caring for a sick child caused isolation, interferes with caring for other children and impacted on socialisation with partners, families and friends. Many parents suffered some degree of anxiety and/or depression, and had poor or fair general health. Most parents experienced a significant degree of difficulty travelling to PMH and found parking there difficult. This included issues of transporting their child from their vehicle to the hospital site. This problem was also experienced when travelling to other health services, though not as significant.

The most helpful and easily accessible PMH services included: other services (e.g. orthotics, Kalparrin, pharmacy, speech pathology), physiotherapists, and occupational therapists. The most helpful and easily accessible community services included: local GPs, DSC, and other health services (e.g. Rocky Bay, school health and school dental services, Spina Bifida Association, Riding for the Disabled).

Most parents relied on support from their immediate and extended family – mainly from grandparents. Almost half of parents used government or privately funded respite provided either in their own home, institutions (such as Lady Lawley, Catholic Care, Rocky Bay, or Red Cross), or in the homes of carers and other family members. The waiting period for respite ranged from 2 months to 3 years, with an average waiting time of 10 months. A third of parents stated they would use a children's respite centre if it were available. Many parents envisaged they would reach a point where they could no longer care for their child and were investigating other arrangements.

Care-related needs rated highly included the need to: know how to obtain equipment to assist with care of their child; have home visits from hospital staff; and to know ways of maintaining a normal lifestyle with their child.

Service and resource needs rated highly included the need to know about what financial assistance is available, have access to more specific sources of information about child's condition, and have practical help with child at home.

Family needs rated as most important included the need to: feel that the health care professionals were sincere in caring about child, to know questions could be asked at any time, and to be told when and why changes were being made in child's treatment plans. Needs that were not well, or, not met at all included the need to: know when to expect side effects to occur, feel there was hope, and have trust in the health-care system.

# ONCOLOGY COHORT

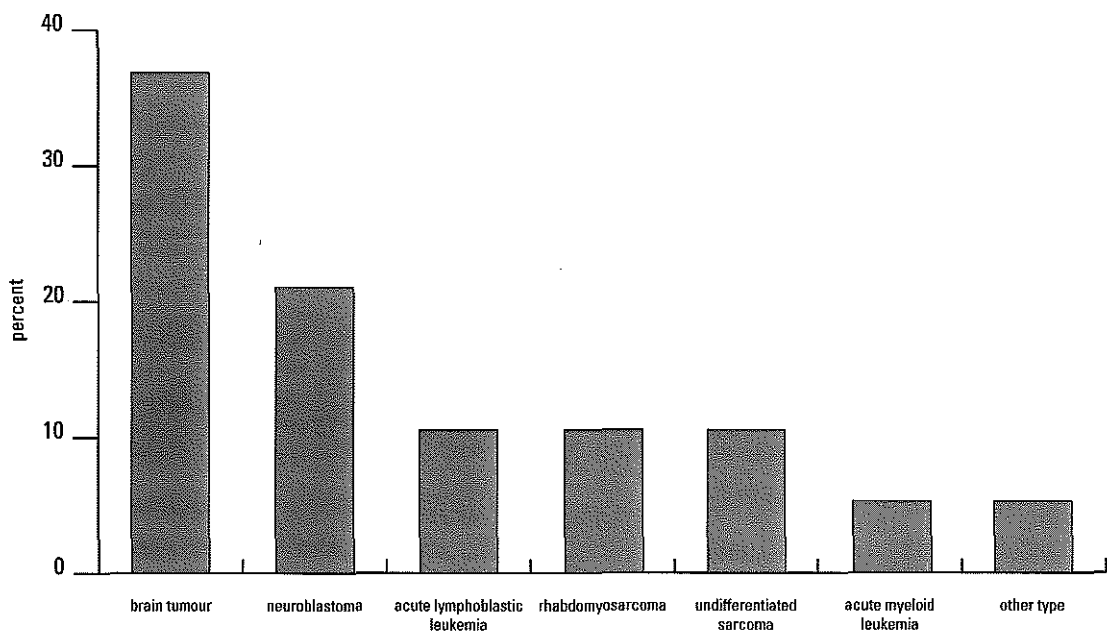
Twenty parents were interviewed, of whom 19 were bereaved and 1 parent was caring for a child receiving palliative care. Results are shown for the bereaved parents only.

## DEMOGRAPHIC CHARACTERISTICS

### Children's demographics

Figure 10 shows diagnostic categories at the time of death.

- Brain tumours – medulloblastoma (n=3; 15%); other (n=4; 21%)
- Neuroblastoma (n=4; 21%)
- Acute lymphoblastic leukaemia (n=2; 11%)
- Rhabdomyosarcoma (n=2; 11%)
- Undifferentiated sarcoma (n=2; 11%)
- Acute myeloid leukaemia (n=1; 6%)
- Other (n=1; 6%)



**Figure 10. Children's cancer diagnosis**

### Treatment

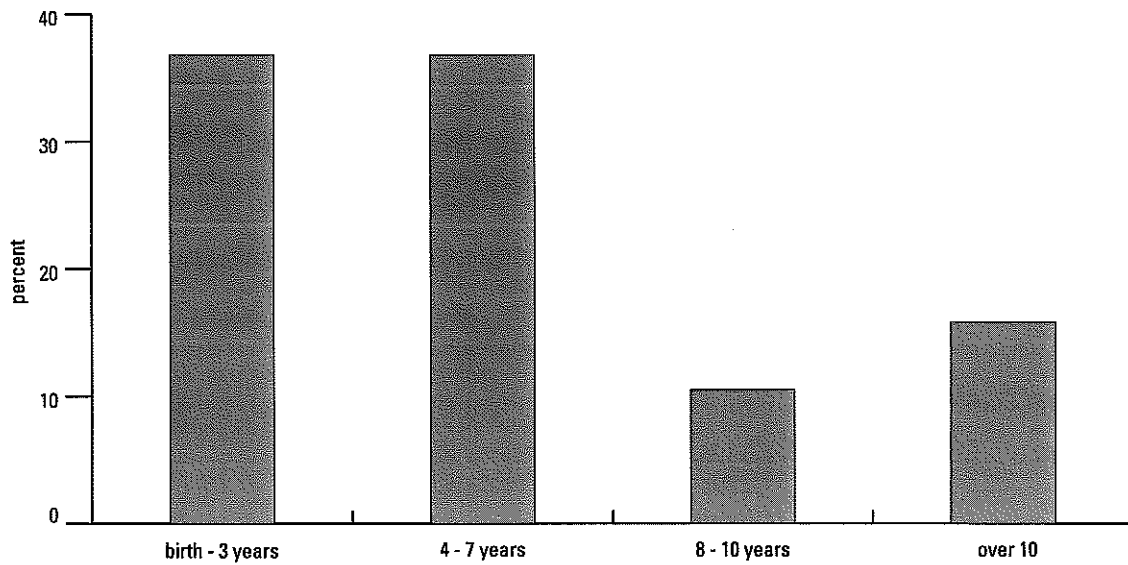
- All children (n = 19; 100%) underwent chemotherapy
- 13 (68%) children had radiotherapy
- 16 (84%) children had surgery
- 9 (47%) children had no episodes of relapse
- 3 (16%) children experienced 2 relapses
- 1 (5%) child experienced 4 episodes of relapse

As shown in Table 16, the mean age of children at diagnosis was 6.0 years (SD 4.5). The mean age of children at the time of death was 8.7 years (SD 4.3). The mean duration of treatment was 2.7 years (SD 2.7).

**Table 16. Mean age of children at diagnosis and death, and treatment duration in years.**

	Mean	SD	Median	Range
age of child at diagnosis	6.0	4.5	4.2	1.2 - 15.8
age of child at death	8.7	4.3	8.1	2.5 - 16.5
treatment duration	2.7	2.7	1.4	0.7 - 10.7

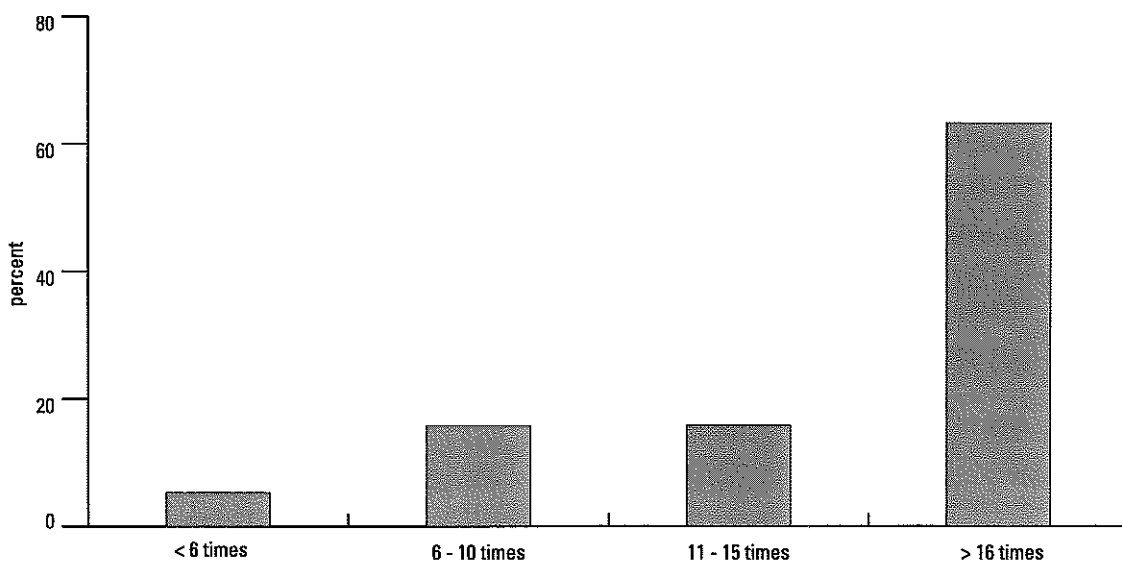
Figure 11 shows the age at diagnosis according to age range in years.



**Figure 11. Age range in years of children at diagnosis.**

#### Hospital attendance

All children received care at PMH. Figure 12 shows that 63% (n=12) of children were admitted to PMH on more than 16 occasions, 3 children 11-15 times (16%), 3 children between 6-10 times (16%), and one child was admitted between 1-5 times (5%).

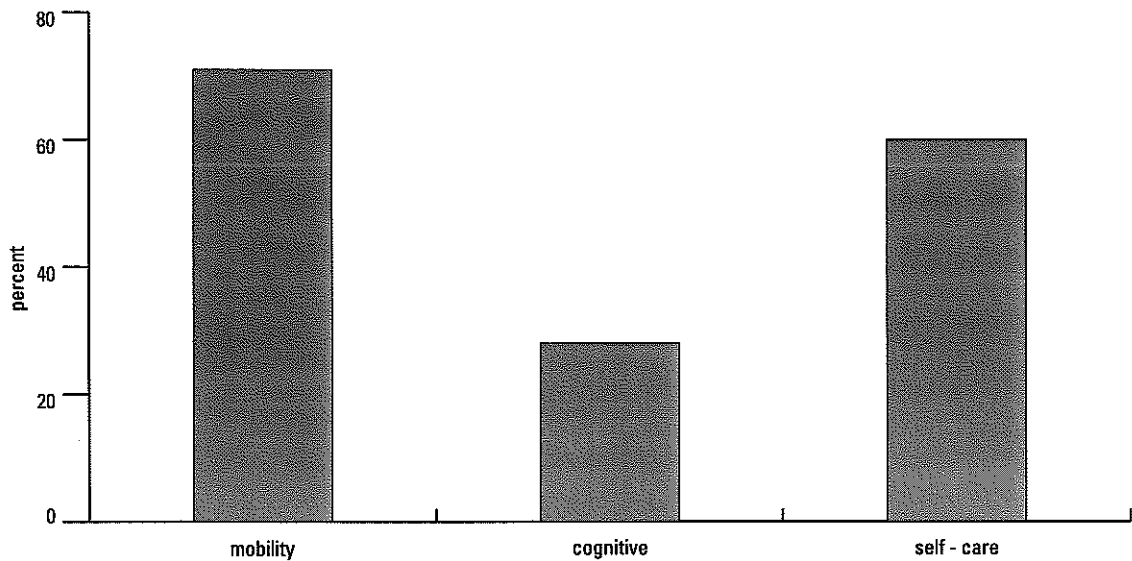


**Figure 12. Frequency of admission of children to PMH for treatment.**

#### Children's functional ability with everyday activities

As previously described, the Wee Fim II was used to measure children's functional ability with everyday functioning. For the mobility domain, the mean score was 1.6 (SD = 0.8); for the cognitive domain the mean score was 2.5 (SD = 0.8); and for the self-care domain the mean score was 1.8 (SD = 0.7). Across all domains 53% (n=10) of children required some help or supervision.

Figure 13 shows a significant proportion of children required assistance with mobility (n=13, 71%), cognitive tasks (n=5, 28%), and self-care (n = 11, 60%).



**Figure 13. Assistance required with daily functioning assessed by the Wee Fim II.**

In the mobility domain, the most highly ranked problems occurred with:

- Coping with bath or shower transfers
- Wheelchairs
- Dealing with movement
- Fourteen children (71%) walked and 5 (26%) children used a wheelchair

In the cognitive task domain, the most highly ranked problems included:

- Expression
- Problem solving
- Social interaction

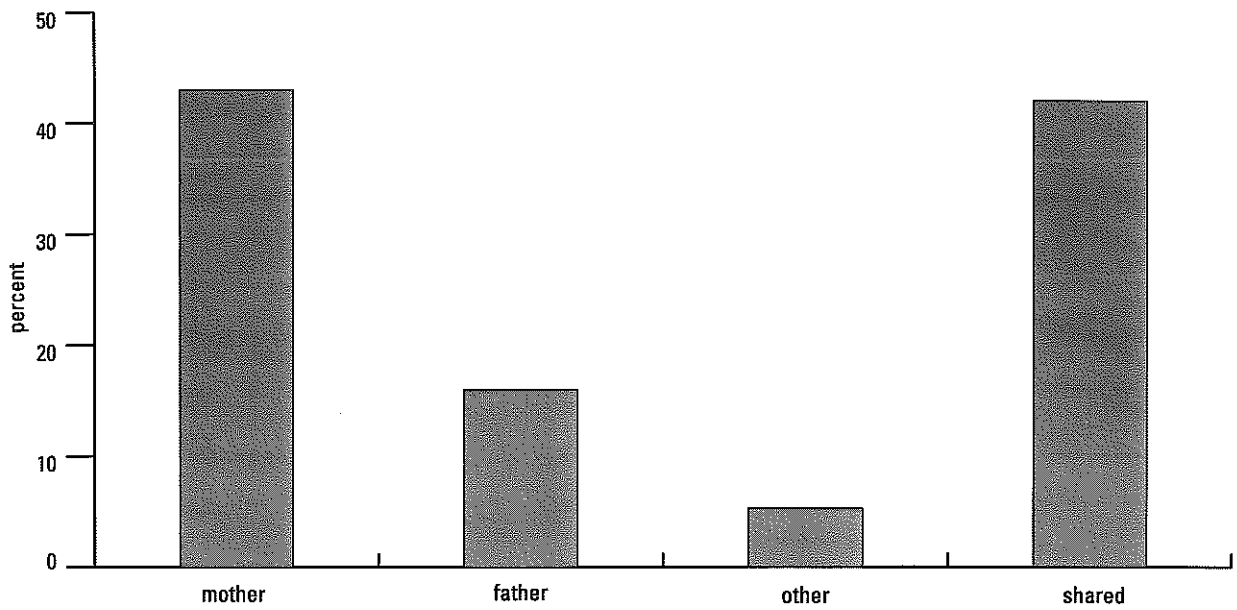
In the self-care domain, the most highly ranked problems included:

- Dressing the lower body
- Bathing
- Dressing both the upper and lower body

#### Parents' demographic details

- 84% (n = 16) of parents resided in the metropolitan area, and 16% (n=3) in rural areas
- At the time of interview the mean age of parents was 38.7 years
- Most parents were aged between 30-40 years (n = 10; 53%); 47% (n=9) were aged between 40-50 years
- 74% (n = 14) of parents were married or living in a defacto relationship and 16% (n = 3) were single parents
- The mean age of parents at the time of their child's death was 37.2 years
- The mean period of mourning was 1.06 years
- 42% (n = 8) of parents had a bachelors degree or higher, 21% (n = 4) no tertiary qualification and 26% (n = 5) had a certificate/diploma
- 62% (n = 12) of parents worked full time
- 32% (n = 6) of parents were full time home carers
- 89% (n = 17) of children held a Health Care Card

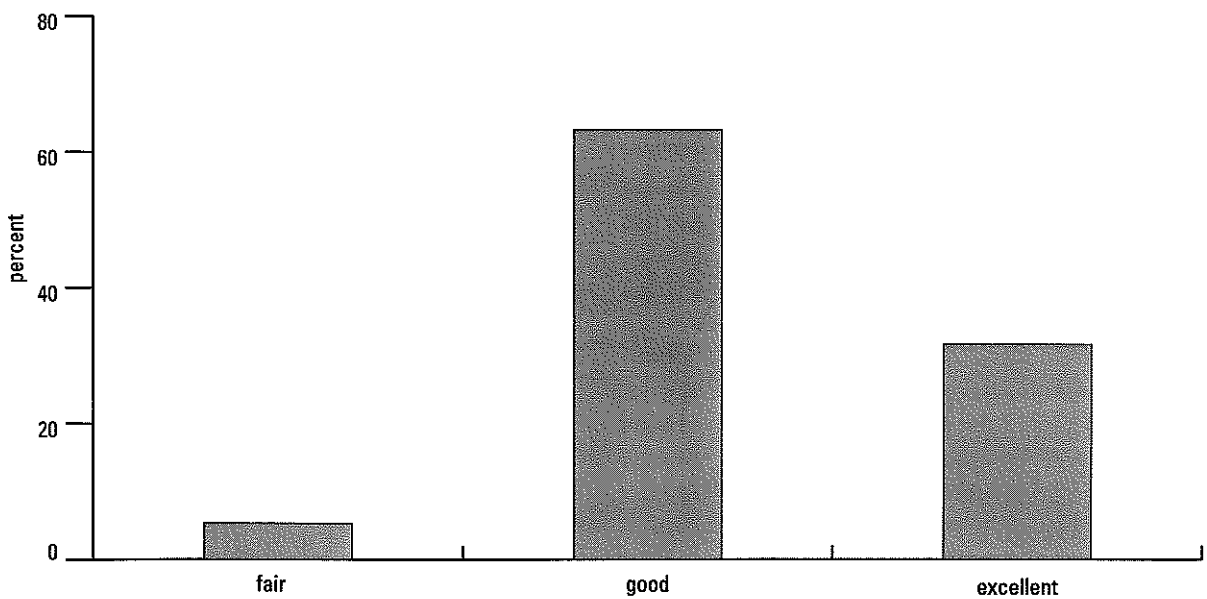
- As shown in Figure 14, 43% (n = 8) of parents interviewed were mothers, and 16% (n = 3) were fathers. Care was shared between mothers and fathers in 42% (n = 8) of cases. One child (5%) was cared for by her grandmother.



**Figure 14. Carer status.**

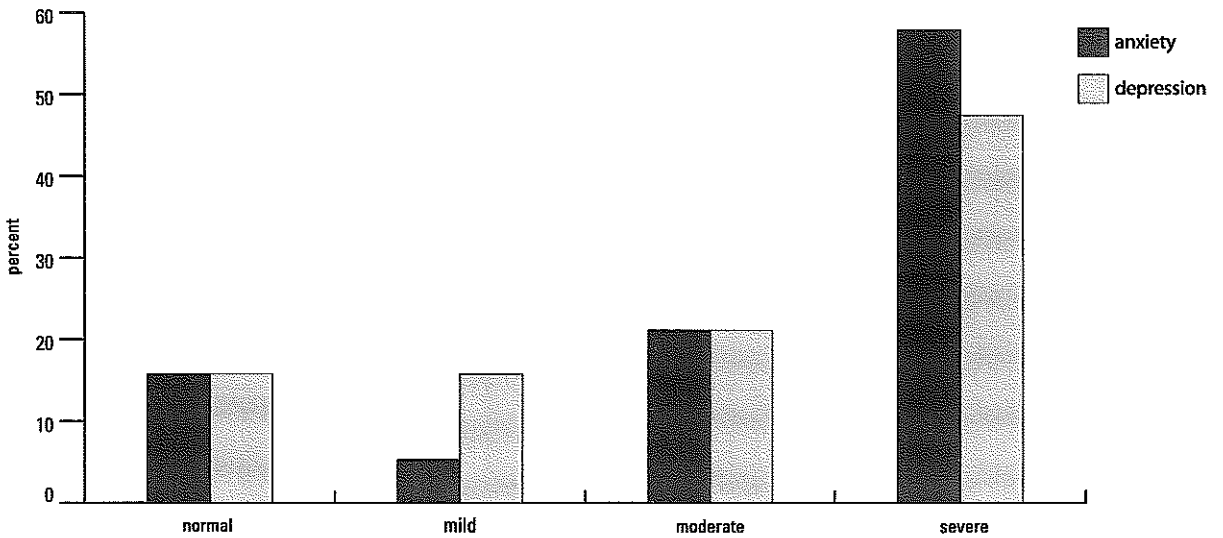
Impact of child's condition on parents and family

As shown in Figure 15, one parent (5%) reported his/her general health as poor, 12 parents (63%) as good, and 6 (32%) parents as excellent.



**Figure 15. General health of parents.**

As previously described, the Hospital Anxiety and Depression Scale (HADS) 26 was used to measure anxiety and depression in the parents of this study. Figure 16 shows that 79% (n = 15) of parents reported moderate to severe anxiety, and 69% (n = 13) reported moderate to severe depression.



**Figure 16. Anxiety and depression in parents as measured by the HADS.**

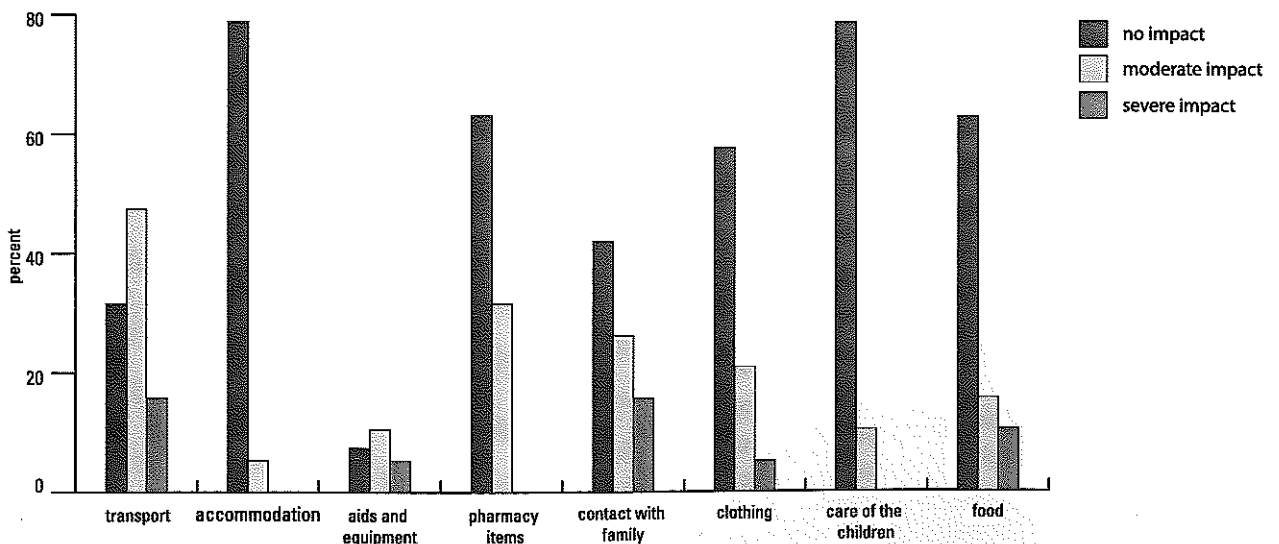
Table 17 shows that over 74% (n=14) of parents reported a moderate to very high overall financial impact from caring for their sick children.

**Table 17. Overall financial impact of caring for a sick child (N=19).**

Overall financial impact	n	(%)
Small	4	21.1
Moderate	5	26.3
High	3	15.8
Very high	6	31.6

\*Missing values

The majority of financial costs related to transport, pharmacy items and maintaining contact with other family members (Figure 17). Only 36.8% (n=7) of parents had access to transport benefits, and only 21% (n=4) had access to accommodation benefits.



**Figure 17. Costs contributing to overall financial impact of caring for a sick child.**

### Travel to PMH for outpatient appointments

- 83% of parents used a private car for transport to PMH
- 67% of parents who resided in the metropolitan areas took less than 30 minutes to reach PMH, 22% of parents took between 1/2 to 1 hour to reach PMH, and 28% took between 1 to 3 hours to reach PMH. Generally, the travelling distance was < 50 km
- 13% of parents residing in rural areas travelled to Perth by air
- 34% of parents experienced difficulty travelling to PMH
- 22% of parents stated that finding parking was very difficult

### **KEY HEALTH PROFESSIONALS, SERVICES AND RESOURCES AT PMH**

Section of 1 the SERU questionnaire was used to explore the use of PMH services (including key health professionals). There were 11 items (key health professionals or hospital services) and parents were asked a yes/no question about whether they had access to, and/or ever used, each professional or service. Parents were then asked how easy it was to access each professional/service, and how helpful these were using Likert-type scales ranging from 0 - 4 (0 = not at all, to, 4 = extremely). Results represent items rated as either 3 or 4 (Table 18).

**Table 18. Frequency of access, ease of access, use and helpfulness of key health professionals and services at PMH (N=19).**

PMH health professionals and services	Had access		Ease of access		Frequency of use		Helpfulness	
	n	%	n	%	n	%	n	%
Specialist oncology doctors	19	100.0	13	68.4	19	100.0	12	63.2
Oncology liaison nurse	19	100.0	14	73.7	19	100.0	14	73.7
Children's activity co-ordinator	18	94.7	15	83.3	17	94.4	14	82.3
Dietician	17	89.5	15	88.2	16	94.1	9	56.2
Social worker	17	89.5	15	88.2	17	100.0	13	76.5
Physiotherapist	16	84.2	9	56.2	12	75.0	7	58.3
Occupational therapist	16	84.2	13	81.2	15	93.7	13	86.7
Pain Team	12	63.2	8	66.7	10	83.3	8	80.0
Dentist	10	52.6	7	70.0	7	70.0	5	71.4
Psychologist	7	36.8	5	71.4	4	57.1	2	50.0
Other services (see Table 19)	5	26.3	4	80.0	5	100.0	3	60.0

**Table 19. Other services at PMH used by children and their parents.**

Education team

Malcolm Sargent Fund

Murdoch Hospital and Sir Charles Gairdner radiology departments

Ronald McDonald House of Life

Starlight Foundation



Key PMH professionals and services most frequently used were: oncologists, the oncology liaison nurse, and other services. Key professionals and services easiest to access were the dietician, social worker, and children's activity co-ordinators. Most helpful key professionals and services were the occupational therapist, children's activity coordinator, and pain team.

#### Resources at PMH

Parents were asked to rank resources at PMH according to frequency of use and helpfulness. Table 20 reflects parents who ranked the resources as either very or extremely useful.

**Table 20. Frequency of use and helpfulness of resources at PMH (N=19).**

	Frequency of use		Helpfulness	
	n	%	n	%
Education by staff about how to care for your child at home (e.g. nasogastric feeding, central line care)	18	100.00	17	94.44
General information from nurses on the ward	16	88.89	13	81.25
Chemotherapy information sheets	15	83.33	9	60.00
Information from oncology liaison nurses	15	83.33	11	73.33
Printed material (e.g. newspapers, magazines, books, medical journals)	15	83.33	9	60.00
Information or advice from family and friends	14	77.78	1	7.14
Internet sites about cancer and treatments	13	76.47	9	69.23
Support groups or programmes from Camp Quality, Canteen or Seize the Day	11	61.11	8	72.73
Pamphlets on specific diseases	9	50.00	3	33.33
Practical aids for teaching (e.g. dolls)	8	44.44	5	62.50
Programmes/courses about cancer from the WA Cancer Foundation	2	11.76	1	50.00
Educational videos	1	5.88	1	100.00
Audio-visual material (e.g. television, audio-tapes, videos)	1	5.88	0	0.00
Programmes/courses about cancer from the Leukaemia Foundation	0	0.00	0	0.00

The PMH resources most frequently used and "most helpful" were: education by staff about how to care for child at home, general information from nurses on the ward, and chemotherapy information sheets.

## COMMUNITY SERVICES AND RESOURCES

Parents were asked to rank key community services and resources according to frequency of use (Table 21). Parents were then asked to rank these according to ease of access and helpfulness. Results reflect parents who ranked these services and resources as either: very or extremely easy to access, and very or extremely helpful.

**Table 21. Frequency of access, ease of access, use and helpfulness of community resources (N=19).**

Community services and resources	Had access		Ease of access		Frequency of use		Helpfulness	
	n	%	n	%	n	%	n	%
Local general practitioner	16	84.2	13	81.2	11	68.7	7	63.6
Support services (i.e. school, neighbour, church)	13	68.4	11	84.6	13	100.0	11	84.6
Local public hospital	10	52.6	8	80.0	6	60.0	6	100.0
Complementary medicine practitioners	7	36.8	4	57.1	2	28.6	1	50.0
Community oncology nurse (Silver Chain)	6	31.6	5	83.3	6	100.0	6	100.0
Local public hospital with a paediatric facility	6	31.6	4	66.7	5	83.3	5	100.0
Local private hospital	6	31.6	5	83.3	1	16.7	0	0.0
Local paediatrician	5	26.3	3	60.0	3	60.0	3	100.0
Local private hospital with a paediatric facility	4	21.1	4	100.0	0	0.0	0	0.0
Other health services (i.e. child health nurse, local pharmacy)	2	10.5	2	100.0	2	100.0	2	100.0

Community services most frequently used were: support services, local GP, and local public hospital (with and without a paediatric facility). Community services easiest to access were the local private hospital (with and without a paediatric facility) and other health services, support services, and Silver Chain nurses. Most helpful community services were the Silver Chain Nurse, local paediatrician, and local public hospital (with and without a paediatric facility).

## RESPIRE AND SUPPORT

- 78% of families relied on support from their immediate family
- 38% of families relied on support from their extended family
- 11% of families used government funded or private in home respite
- 6% of families used government funded or private residential care
- 83% of parents stated they had not used respite services because they had either chosen not to use respite, or felt that use of respite was not applicable to their child or family

## CARER NEEDS

The Patient Carer Needs Survey (PCNS) was used to determine the needs of parents. The PCNS comprised 14 items (i.e. needs). For each need, parents were asked to respond to three separate Likert-type scales ranging from 0-4. These scales measured the perceived importance of the need (0 = not at all important, to, 4 = extremely important), how well the need had been met (0 = not a need, to, 4 = completely met), and whether parents would have liked to learn more about the particular need (0 = not at all, to, 4 = a great deal). Results for items scored as either 3 or 4 are shown in Table 22.

**Table 22. Needs of parents (N=19).**

Patient care needs	Important		How well met		Need more information	
	n	%	n	%	n	%
To know about ways to help keep my child comfortable.	16	88.9	5	29.4	5	29.4
To have home visits by health professionals as needed (eg. for injections or taking blood).	16	84.2	4	21.0	5	27.8
To have equipment to help with my child's care (e.g. nasogastric pump, bathing).	15	83.3	0.00	0.00	1	5.9
To know about ways to provide my child with adequate nutrition.	14	77.8	5	27.8	5	27.8
Assistance in methods of pain control for my child.	14	77.8	6	33.3	4	22.2
To know about ways to help me cope with my child's condition.	14	73.7	8	44.4	9	50.0
To know ways to deal with changes to my child's activity/ability levels.	13	72.2	7	41.2	7	41.2
To know ways to maintain a normal lifestyle with my child.	13	68.4	4	23.5	5	31.2
To know about activities to help my child feel occupied when activities are restricted.	12	66.7	6	37.5	6	37.5
To know what information to give to my child (appropriate to his/her age) about his/her condition.	12	63.2	6	33.3	5	29.4
Information about nutritional drinks for my child.	9	56.3	5	33.3	3	20.0
Information about how to get my child to eat.	9	52.9	4	25.0	5	31.2
To know ways to help my child feel better about his/her appearance.	6	35.3	1	6.7	0	0.0
To know ways to overcome problems with clothing and accessing devices.	5	29.4	1	7.1	0	0.0

The highest rated carer needs were: to know about ways to keep a child comfortable, to have home visits by health professionals (hospital) as needed, and to know how to obtain equipment to help with child's care.

Highest rated carer needs that were not as well met as expected by parents were: to know about ways to help cope with child's condition, to know ways to deal with changes to child's activity/ability levels, and to know about activities to help child feel occupied when activities are restricted.

Highest rated carer needs for more information were: to know about ways to help cope with child's condition, to know ways to deal with changes to child's activity/ability levels, and to know how about activities to help child feel occupied when activities are restricted.

## SERVICE AND EDUCATIONAL NEEDS

Section 7 of the SERU explored the specific carer needs that were related to services and education. As previously explained, results for items scored as either 3 or 4 are shown in Table 23.

**Table 23. Carer needs related to service and education needs (N=19).**

Carer service and educational needs	Important		How well met		Need more information	
	n	%	n	%	n	%
To have access to health care professionals' advice out of regular hours	16	88.9	6	33.3	6	33.3
To have access to more specific sources of information, including palliative care	13	72.2	7	38.9	9	50.0
To know about what financial assistance was available (e.g. PATS, Malcolm Sargent Fund,)	11	61.1	3	17.6	4	25.0
To know more about the role of other medicines for my child (e.g. antibiotics, anti-sickness)	9	50.0	2	11.1	2	11.8
To know about local health care resources while at home	9	50.0	4	23.5	5	31.2
Help in administering medications to my child	8	44.4	4	25.0	3	20.0
To have practical help with my child at home	7	41.2	2	14.3	2	14.3
To know about school/day care options for my other children	7	38.9	2	13.3	1	7.7
To know about complementary medicines and treatments for my child (e.g. vitamins and herbal tonics)	6	33.3	6	33.3	5	29.4
To know more about managing travel and distance issues	3	16.7	2	12.5	2	14.3

The most important service and educational needs were: to know about ways to help keep child comfortable, to have home visits by health professionals as needed, and to have equipment to help with child's care.

Highest rated service and educational needs not as well met as expected by parents were: to know about ways to help cope with child's condition, to know ways to deal with changes to child's activity/ability levels, and to know about activities to help child feel occupied when activities are restricted.

Highest rated carer needs for more information were: to know about ways to help cope with child's condition, to know ways to deal with changes to child's activity/ability levels, and to know about activities to help child feel occupied when activities are restricted.

## FAMILY NEEDS

The Family Inventory of Needs – Paediatric (FIN-PED) was used to determine the needs of parents. As previously explained, results for items scored as either 3 or 4 are shown in Table 24.

**Table 24. Family needs (N=19).**

Family needs	Important		How well met		Need more information	
	n	%	n	%	n	%
To know when to expect side effects to occur	19	100.0	5	26.3	6	31.6
To have thorough information about how to care for my child at home	18	94.7	6	31.6	7	38.9
To know I could ask questions any time	18	94.7	1	5.3	5	29.4
To be informed of changes to my child's condition	17	94.4	6	33.3	10	58.8
To know what treatment my child was receiving	17	94.4	1	5.6	6	33.3
To feel that the health care professionals were sincere in caring about my child	17	94.4	2	11.1	5	27.8
To have explanations given in terms that were understandable to me	17	94.4	1	5.6	5	27.8
To be told when and why changes were being made in my child's treatment plans	17	94.4	1	5.6	4	22.2
To have trust in the health-care system	17	89.5	4	21.1	7	38.9
To know what side effects the treatment can cause	16	88.9	3	16.7	5	27.8
To know that health-care professionals would offer me the opportunity to participate equally in my child's care	16	88.9	0	0.0	2	11.1
To know to whom I should direct my questions	16	88.9	5	27.8	8	44.4
To know the probable outcome of my child's illness	16	88.9	4	22.2	5	27.8
To feel there was hope	14	77.8	5	29.4	3	17.6
To know how to give information to my other children (appropriate to his/her age)	12	66.7	3	16.7	5	27.8
To know what information to give to my other children (appropriate to his /her age)	12	66.7	5	27.8	6	33.3
To know how to handle the feelings of my other children	12	66.7	5	27.8	5	27.8

The most important family needs were: to know when to expect side effects to occur, to have thorough information about how to care for child at home, and to know questions could be asked at any time.

Highest rated needs that were well not well met were: to be informed of changes to child's condition, to have thorough information about how to care for child at home, and to feel there was hope.

Highest rated needs for more information were: to be informed of changes to child's condition, to know to whom questions should be directed, and to have thorough information about how to care for child at home.

## **SUMMARY OF PHASE I FINDINGS FOR ONCOLOGY COHORT**

A typical parent interviewed in this cohort had been bereaved for approximately one year, was aged between 30 and 50 years, residing in the metropolitan area, suffered from moderate to severe anxiety and/or depression, and had suffered a high financial impact as a result of their child's illness. The mean age of the child at diagnosis was 6 years, the mean treatment duration was 3 years, and children had required up to 16 admissions to hospital. The majority of parents cared for their children at home during palliation. Most children required assistance with daily functioning such as mobility, self care and cognitive function. Most parents prefer and rely upon support from family and friends. Little use was made of respite (either in-home or residential).

The most easily accessed and helpful key PMH professionals and services were: the oncology liaison nurse, social worker, and dietician. The PMH resources most frequently used and most helpful were education by staff about how to care for child at home, general information from nurses on the ward, and chemotherapy information sheets.

The most frequently easily accessed and helpful community resources were the local GP, local public hospital (with and without a paediatric facility), and the Silver Chain Nurses.

Care-related needs rated highly included the need to: to have home visits by health professionals (hospital) as needed, to know about ways to keep child comfortable, and to know how to obtain equipment to help with child's care. All of these needs were perceived as not well met.

Service and educational needs rated highly included the need to: have access to health care professionals' advice out of regular hours and more specific sources of information (including palliative care); to know more about financial assistance; and the role of other medicines for child. These needs were also perceived as not well met.

Highly rated family needs included the need to: feel hope, have access to home care, and trust the health care team. These needs were not as well met as parents had expected.

# Phase II

This phase comprised in-depth interviews with parents and service providers to further explore the major issues identified in Phase I (i.e. the concept of palliative and supportive care, the need for family respite, potential use of a children's hospice facility, and issues related to care of a sick child including the emotional and financial impact).

## PARENT INTERVIEWS

### Recruitment process for parent interviews

Those parents who in Phase I, agreed to be contacted regarding participation in Phase II were approached by telephone by the research assistant. If parents agreed to participate in this phase, they were sent an information sheet, a consent form and reply paid envelope. Upon receipt of the signed consent form, the research assistant contacted each parent by telephone and arranged an appointment time to conduct the Phase II interview either face-to-face or by telephone.

Fifteen parents from the oncology cohort interviewed in Phase I agreed to be approached for participation in Phase II. Thirteen consents were received, and 10 interviews were completed (rural parents = 2, metropolitan parents = 8).

Ninety one parents from the non-oncology cohort agreed to be approached. All parents were approached because the researchers wished to ensure the data obtained represented parents of children from each of the previously described disease categories. Forty-five consents were received and 28 interviews undertaken.

A total of 38 interviews were undertaken involving both cohorts: 10 for oncology, and 28 for non-oncology. The distribution of Phase II interviews according to disease category and location is show below in Table 25.

**Table 25. Distribution of Phase 2 interviews according to disease category and location.**

Disease category	Invitations	Consents	Rural interviews	Metropolitan interviews	Total
1	15	13	2	8	10
2	8	4	2	2	4
3	14	11	2	6	8
4	56	25	5	6	11
5	13	5	0	5	5
<b>Total</b>	<b>106</b>	<b>58</b>	<b>11</b>	<b>27</b>	<b>38</b>

### Analysis of parent interviews

Each interview was audio-taped and then transcribed. Transcriptions were analysed using the technique of content analysis. Open coding was used to identify common themes. Nine themes were identified and are presented with parents' perceptions.

# KEY THEMES IDENTIFIED FROM PARENT INTERVIEWS

## **The experience caring for a sick child.**

### Non-oncology cohort

- Many parents accepted their experience of caring for their child as a fact of life
- Many parents had developed their own coping strategies (e.g. alternative therapies to keep their children in optimal health)
- Many children received care from health professionals through the school he/she attended (e.g. occupational therapy, physiotherapy and speech therapy)
- Parents spoke frequently about difficulties procuring funding for the various types of care their children required, and perceived barriers and inequities (e.g. other children with similar disabilities receiving different funding allowances)
- The 'LAC' (local area co-ordinator) was often the person who helped parents in practical matters such as funding and equipment for the home
- Parents on the outer metropolitan fringe (i.e. Mandurah and beyond) spoke of the difficulties, due to distance, of accessing facilities at Rocky Bay and Princess Margaret Hospital
- Parents, especially mothers, had concerns about the care of their children as they reached the teenage years (i.e. physical size and weight). Several parents had back problems
- Care of children requiring mobilisation in wheelchairs often required building a special house or improving facilities in the home for which cost was a major factor
- Parents who were renting required help from the State Housing Commission, and had some difficulty in finding suitable accommodation
- Parents in rural areas found local support groups important in accessing facilities in the country, and for moral support
- School support was important as a form of respite, support to parents, and counselling for siblings
- A major aspect of care was the personal care required to prepare a child for school, and ongoing toileting requirements
- Some parents found the physiotherapy requirements of their child difficult to sustain (e.g. discomfort experienced by the child during therapy sessions, or a lack of co-operation from the child)

### Oncology cohort

- Perception of the experience was affected by the duration of the illness and period of time since the child's death
- Personal relationships with caregivers were important, but many parents described a wish for privacy for the family
- Many parents preferred to look after their dying children at home when they could, and often stated that they tried to take their child home as soon as possible after outpatient treatments
- Most children preferred to be at home when dying, although the ability to express this wish varied with the age of the child and with their condition
- Support from family and friends were important to many parents
- Spousal support was important in caring for the child for most mothers, especially when the child was in hospital
- Difficulties in parental relationships (e.g. separation or divorce) impacted negatively on the parental perception of the child's illness and death
- Rural parents were concerned that access to specialist help/advice was difficult and time consuming and contributed to the stress when caring for their child at home



## **Use of, and preferences for, respite care (in-home care or residential care).**

### Non-oncology cohort

- Most parents of children with disabilities used some form of respite
- Use of in-home and residential care was mixed, but many parents and children had a preference for either one or the other
- Parents needed to be confident their child was well-cared for. Some parents felt a lack of privacy with in-home support
- School was viewed as a form of respite for most parents
- For many, respite arrangements had taken a considerable time to arrange
- A considerable number of parents did not feel they had sufficient respite time

### Oncology cohort

- Parents of children with cancer wanted to be with their child as much as possible while in hospital, and used their partner or close family members for respite
- At home, many parents stated that both they and their child liked to keep everything as normal as possible, by attending school where possible, and maintaining contact with friends
- During the terminal phase, most parents preferred to be with their children where possible. Some felt they had extra stamina at this time, and felt naturally inclined to be the carer for their children
- Parents felt their children shared this sentiment
- Parents preferred to care for their children at home during the terminal phase of their child's illness
- Most children who were able, expressed a desire to be at home during the palliative phase of their illness

## **Parents' understanding of/and introduction to concept of "palliative care".**

### Non-oncology cohort

NB: The term "supportive" rather than "palliative" was used for this cohort in accordance with advice from PMH clinicians who perceived this cohort of parents would be particularly sensitive to the term "palliative" care.

- Many parents were not really sure of what was meant by "supportive care"
- Many parents with children who suffered from conditions with declining health found it difficult to discuss a palliative phase in their child's illness, although frequently admitted to thinking or worrying about their child's future
- Parents with children requiring complex care did not like to burden their well children with care of the sick child, and were concerned for the future of the well child
- Some doctors had discussed the possible outcome of the child's illness at diagnosis, but not in recent times
- Many parents felt they had ongoing support from their doctor, and that the matter would be addressed in time
- Some doctors were perceived by parents not to have addressed the issue of "supportive care" and parents felt they had no support from their doctor regarding this issue
- Some parents felt their child's doctor assumed the parent would understand the eventual outcome of their child's illness after offering a diagnosis, and did not realise they would like to discuss the matter further
- Some parents of children with long-term illnesses were sometimes not in frequent touch with the child's paediatrician
- Some parents felt the doctor's explanation of the prognosis as insufficient
- Many parents given explanations of the diagnosis of a serious life-limiting conditions felt the doctor was too considerate, and had tried to explain the condition without actually underlining the severity of their child's illness
- Many children's conditions were perceived by parents to have been diagnosed in a fragmented fashion
- Some parents perceived their child's illness/condition had an inevitable outcome, and there was no use therefore in discussing this situation with the doctor

### Oncology cohort

- Most parents perceived palliative care as care for a child no longer receiving acute care, i.e. care of a dying child
- Some parents perceived the care of their child as palliative from the time of diagnosis, due to the severity of the condition, or due to treatment options offered, as well as when specifically told so by their oncologist
- Parents felt introduction of the concept was linked to a specific test or episode of illness
- Many parents felt they were kept well-informed

## **Potential use of a Children's Respite Centre/Hospice if it had existed.**

Preamble - *There is an association (Children's Hospice Association Inc) wishing to build a freestanding home, which would offer special care for children and respite for their carers, palliative care for those children and their families who may require it, and bereavement support if required.*

### **Non-oncology cohort**

- Many parents stated they might use the facility if it were accessible to them
- Some parents felt it would be useful to their child, as long as there was a period of familiarisation before a long stay
- Many parents were happy with the respite currently offered, such as Rocky Bay, and were already using this service for longer stays
- Many parents were happy with the type of arrangements they had at present, but felt they would use them more often if they had more access and/or funding to purchase respite
- Parents were concerned that a hospice aimed at a more general population of children with life-limiting conditions might find it harder to provide the skilled care their child required

### **Oncology cohort**

- Many parents wanted to care for their children at home
- Metropolitan parents felt a hospice might be useful for country people
- Many country people wanted to look after their children at home, but felt the distances involved in travelling to PMH placed extra stress on their families

## **Parents' expectations of carers.**

### **Non-oncology cohort**

- Professional carers or other persons who offer regular respite were often seen as important in the care of the child and family
- Professional carers who cared for children on a regular basis were highly valued, as many parents felt it took considerable time and effort to train a carer to care adequately for their child
- School facilities were important to parents of children requiring a lot of supportive care (e.g. physiotherapy, speech therapy and occupational therapy) as these are regular and easily accessible

### **Oncology cohort**

- Many parents expressed positive views about PMH staff involved in the care of their child, however there were key staff who were viewed as very important to the child and/or the family
- The paediatric oncologist at PMH was often regarded as a key person in the care offered in hospital, and their availability out of hours for support and advice was valued
- Parents stated they and their child valued school attendance at PMH as retaining a sense of normality for the child when well enough
- Visits from medical and nursing staff at PMH when children were receiving palliative care at home were seen as supportive, even if the parents and family undertook most of the actual care
- Many parents saw their extended family and friends as key support people
- If more adequate paediatric oncology medical and nursing services had existed in country areas, parents felt their family's palliative experience would have been a lot less stressful
- Metropolitan parents felt there was a lack of specific paediatric knowledge and experience among community-based nursing and medical staff that cared for their dying child at home. There was a lack of familiarity by nurses with medication doses for children (especially morphine). Parents perceived a lack of nursing staff, especially at night

## **Level of contact from PMH & other staff for non-oncology cohort, and PMH staff for oncology cohort**

### Non-oncology cohort

- Parents of children with long-term life-limiting conditions often have minimal contact with PMH staff and this was not perceived to be a problem
- Many parents and children who do have regular appointments with their paediatrician at PMH viewed the allocated consulting time as sufficient
- Care at PMH is often seen as supportive or advisory only, and parents try to keep their children well enough to avoid hospital stays
- Local area co-ordinators from DSC were seen as helpful and important for moral support

### Oncology cohort

- Parents often stated they felt very supported by PMH oncology staff, and found it hard when contact decreased or ceased after their child's death
- Some parents stated they would have liked more contact with staff after their child died, although they did not want to visit the hospital to do this
- Some parents felt they would have liked to discuss issues around their child's palliative care, such as pain management and nutrition, and would have liked to be more informed about the process of death
- Some parents expressed concern about not feeding their dying child
- The children's activity co-ordinator was important to many children and parents
- The social worker, Home Visiting Nurse, and the Pain Management Team from PMH during palliative phase were considered helpful
- Parents complained about long waiting lists for procedures and that morning procedures were seen as most practical
- Some parents feel a certain disregard to timing of procedures (e.g. when planned during meals or other important activities)
- Some parents felt insufficient attention was given to pain medication issues during the palliative phase
- Some parents felt it was difficult to be together as a family during treatment in hospital

## **What was most important to the child and family during the last months of life?**

### Non-oncology cohort

- Funding to obtain respite, aids and equipment (i.e. hoists, wheelchairs)

### Oncology cohort

- Most parents felt it was most important to be together as a family, and to spend as much time together as possible
- Some parents felt the demands of visiting friends and extended family made this difficult
- Pain management was mentioned as an issue for some children. Parents were relieved when intractable pain issues were resolved
- Some parents said their child wanted to spend time with friends, although for many this changed as they became more incapacitated

## **Management of other children and suggestions for improvement.**

### **Non-oncology cohort**

- Well siblings had difficulty dealing with deterioration in their sibling's health and found it hard to discuss the issue of their premature death
- Parents were aware of the needs of their other children, and tried hard to ensure all children receive the same attention and opportunities for entertainment
- Many parents make a conscious effort to ensure their healthy children do not feel responsible for the care of their disabled sibling

### **Oncology cohort**

- Parents felt family life was difficult to maintain when they have a sick child
- Some parents felt their other child or children were neglected at times
- Due to distance issues, rural parents found it hard to manage to care for other children who needed to attend the local school "in town"
- Children found it hard to deal with the illness and death of a sibling. Some siblings found this more difficult than others
- Some children required counselling at the time of their sibling's death and subsequently during the mourning period
- Many parents felt their other children have ongoing issues about the illness and death of their sibling

## **How parents' emotional needs were met, and how they felt at the time of the study.**

### **Non-oncology cohort**

- Many parents stated they were physically worn out at times
- Some parents have back problems associated with the lifting of their child
- Parents have difficulty going away or out as a couple due to the lack of appropriate care for their child and commented that this placed a strain on their relationships
- Parents had feelings of isolation and lack of social opportunities
- Parents stated that respite did help, although they often worried about their child while they were not with them
- Help with the physical care of their child and toileting tasks is seen as important for many parents' well-being

### **Oncology cohort**

- Parents did not focus on their own well-being throughout the trajectory of their child's illness or death
- Parents experience more emotional issues following their child's death than during the care of their sick child
- Some parents have not spoken in detail about the death of their child to anyone
- Parents felt they would value more inquiries about the well-being of the family by some of the staff who looked after their deceased child
- Some parents felt counselling might help them

# SERVICE PROVIDER INTERVIEWS

Semi-structured interviews were undertaken with service providers to determine the extent of services provided, client eligibility criteria, waiting times, types of services offered, and the barriers and facilitating factors to service provision. The sample consisted of all service providers identified and used by parents for palliative and supportive care (n = 20). See Table 26.

**Table 26. Service providers of supportive and palliative care as identified by parents in Phase 1.**

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1.	Carers WA
2.	Cerebral Palsy Association
3.	Cystic Fibrosis Association of WA
4.	Disability Services Commission
5.	Hills Community Support Group
6.	Homecare Pursuits
7.	i.d.entity.wa (formerly Catholic Care)
8.	Kalamunda Community Care
9.	The Kalparrin Centre*
10.	Lady Lawley Cottage
11.	Neurological Council of WA
12.	Nulsen Haven
13.	People With Disabilities
14.	Perth Home Care Services
15.	Red Cross WA – Commonwealth Carer Respite Centre
16.	Rocky Bay
17.	Silver Chain – Home Support Services Program
18.	Southcare Inc
19.	The Gowrie (WA) Inc.
20.	Wanslea Home Care Program

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\* Help and support for families of children with special needs.

## Analysis of service provider interviews

Responses to each question were summarised according to perceived facilitating factors to provision of palliative and supportive care.

## **FINDINGS FROM SERVICE PROVIDER INTERVIEWS**

Service providers were asked to describe the services provided by their organisation. Results were categorised according to palliative and supportive care and are detailed below.

### **Supportive care services available**

- PMH
  - Full multidisciplinary care team
- Therapy services / early intervention services (e.g. Cerebral Palsy Association, Rocky Bay, Nulsen Haven)
- Home help (i.e. domestic assistance) and other HACC funded services (e.g. Silver Chain, Southcare)
- Respite
  - In-home care
  - Residential care (often long waitlists)
  - Emergency / crisis care respite (Perth Home Care Services)
  - Brokerage models of respite
- Carer Support Groups
- Carer weekends / camps (particularly for mothers) provided by Kalparrin
- Carer Information
  - Carer's resource packs
  - "Disability First Stop" (information hub for people with disabilities)
  - Kalparrin Drop-in centre
  - Neurological Council of WA
- Carer Counselling (phone or face-to-face)
- Sibling programs
- Carer Education & Training
- Carer advocacy
- Disability Advocacy (People With Disabilities)
- Family Strengthening Programs (Wanslea)
- Pre & post hospitalisation care (Lady Lawley Cottage)
- Recreation programs (Cystic Fibrosis Association of WA, Cerebral Palsy Association, Nulsen Haven, i.d.entity.wa (formerly Catholic Care))
- Equipment & / or Assistive Technology Services (Cerebral Palsy Association, Rocky Bay)
- Alternatives to Employment / Post-School Options Programs (Hills Community Support Group, Rocky Bay, Nulsen Haven)
- Parent-Link Program (Kalparrin)
- Accommodation
  - Group homes for adolescents (Nulsen Haven)
- Child Care
  - Facility based (i.e. Gowrie)
  - Family day care (i.e. Wanslea)
  - In-home child care (i.e. Wanslea)

## **Palliative care services available**

- > PMH
  - Medical and nursing care
- > Lady Lawley Cottage
  - Nursing care
  - Residential care
- > Red Cross WA – Commonwealth Carer Respite Centre
  - In-home or residential care
- > Silver Chain – Home Support Services Program
  - In-home care
  - Counselling support
- > Perth Home Care Services
  - In-home care

The following list provide a summary of the barriers and facilitating factors to supportive and palliative care provision as perceived by the above service providers.

## **Facilitating factors to the provision of supportive and palliative care.**

1. Compassionate, committed skilled staff. Networks and collaboration between different service providers (encouraging continuity of staff / agency involvement).
2. Respite is becoming more individual focused, flexible and responsive.
3. Different models of respite are increasingly becoming available.
4. Availability of emergency / crisis care respite (Red Cross, Perth Home Care Services).
5. Lady Lawley Cottage is able to provide respite for children with very high complex medical needs.
6. Agencies committed to advocating for people with disabilities and carers
7. Introduction of "Disability First Stop" – funded by Disability Services Commission. This is a pilot innovative program that aims to help people with disabilities and their families get the help they need. Disability First Stop has been designed to direct disabled people (following the diagnosis of a disability either from an accident or medical condition) to the appropriate agencies that can provide the specific support required by individuals
8. Use consumers by some agencies to guide service provision (e.g. management boards that comprise at least 50% parents of a child with a disability).
9. Family oriented perspective of many services.
10. Larger services such as Silver Chain who can provide high quality services 24 hours a day, 7 days a week.
11. Many agencies conduct their own staff training and professional development activities, therefore, staff continually up-skilled.

## **Barriers to the provision of supportive and palliative care**

1. Lack of funding available for families to purchase necessary services (i.e. a sufficient number of hours of respite).
2. Lack of funding / adequate resources to enable agencies to provide desired services (e.g. camps for fathers).
3. Uncertainty of future funding for service providers.
4. Lack of central information point. Parents do not know where to start to look for information (DSC attempting to address this issue through the recent launch of "Disability First Stop").
5. Lack of accommodation services – long waiting lists (often several years).
6. Lack of residential care options:
  - a. Long waiting lists – especially for weekends and school holidays.
  - b. Inconsistent criteria.
  - c. Difficulty securing respite for children with challenging behaviours.
  - d. Small but significant number of families who adopt a 'revolving door' approach to using residential care – thereby limiting the availability of beds, and also perceived to not be coping with caring role (this issue is also perceived not to be dealt with).
7. Lack of recognition about growing issue of children with complex medical needs.
8. Lack of carers who are suitably trained to provide in-home care for such children.
9. Lack of beds available for such children in residential care facilities.
10. Growing reality that more children are surviving into adulthood with high medical needs.
11. Lack of workforce planning:
  - a. Poor recruitment and retention of carer staff.
  - b. Low community regard for care staff.
  - c. Inadequate wage scale for carers and typical 'unsociable' hours of work.
  - d. Poor marketing of profession and job prospects.
  - e. Difficulty managing inconsistent demands for services .
12. Concern with existing community-based disability services in terms of palliative support for children:
  - a. Need for more coordination of care on behalf of families.
  - b. Need for better forward planning.
  - c. Need to decrease perceived bureaucratic processes (some decisions take many years).
  - d. Need for broader criteria to accommodate many needs of children .
  - e. Need for increased leadership to organise inter-agency collaboration .
  - f. Need for a case management approach .
13. Unrealistic expectations regarding specific service providers.
14. Narrow eligibility criteria of a number of key service providers.
15. Lack of recognition of ADHD as a disability. There are limited services available for these children and their families (i.e. Red Cross WA).
16. Lack of community and health worker knowledge about already existing services (especially amongst GPs and other medical specialists).
17. Distance Issues related to the vast area of Western Australia – most agencies are poorly resourced to provide rural services.
18. Access / transport issues ( limited parking, limited public transport, limited reserved ACROD Bays).
19. Parents failing to identify themselves as carers and, therefore, not accessing services as they choose to "battle on" independently.
20. Lack of recognition for caring role.
21. Many families in Western Australia are very isolated.



## SUMMARY OF FINDINGS

### **Parent interviews**

Findings supported the major findings of Phase I and provided valuable additional information about the barriers and facilitating factors regarding care provision. As in Phase I, parents preferred to care for their children themselves whenever possible, throughout the trajectory of their illness. Adequate financial and practical assistance are central to care provision, and contribute to the quality of life experienced by children and their parents. Families need access to specialist health care, whether they live in metropolitan or country areas. The concepts of palliative and supportive care are not well understood. Parents require clear information about their child's diagnosis, changes in condition and treatments, however, seemingly non-oncology doctors may fail to provide this information in an effective and timely manner. Parents maintain that professional carers who provide end-of-life care to their children require specific paediatric knowledge and experience. Siblings of ill children are often affected emotionally and parents try not to burden them with the care-giving role by encouraging them to live as normal a lifestyle as possible. Respite is viewed as crucial to the wellbeing of children and their families, however, parents perceive that insufficient respite care is available.

### **Service provider interviews**

There is a wide range of supportive and palliative care services including early intervention therapy, in-home and residential respite care, emergency/crisis respite care, carer counselling and support programs, sibling programs, child care, group homes for adolescents, carer information centres, and home help. However, there is a lack of funding available for families to purchase necessary services (e.g. respite, allied health care), and the criteria for accessing services are narrow and inconsistent. There is a perceived lack of workforce planning and a lack of suitable trained carers. There is a lack of recognition of the caring role, with many families being isolated and "battling on". There are a number of access and travel issues related to inadequate parking, limited public transport and ACROD bays.

Existing community-based disability services require improved coordination between service providers and families, broader criteria to accommodate the needs of children and their families, increased leadership to organise inter-agency collaboration, and a case management approach for families.

# Conclusion

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The philosophical underpinning of international paediatric palliative and supportive care models is that palliative and supportive care should be offered to all children with life threatening or chronic illnesses/disabilities with complex care needs. This approach allows the integration of cure-directed treatment and palliative care, ensuring children can benefit from both philosophies of care. There is increasing recognition for the need to development appropriate paediatric palliative care services, especially in Western Australia where supportive care services for children with life-limiting conditions are significantly underdeveloped. The notable lack of evidence to guide the development of Western Australian paediatric palliative and supportive care services provided justification for our study.

The overall purpose of the study was to better understand the needs of families of children suffering from life threatening conditions in Western Australia, and identify the extent of service provision currently available for these families in order to provide an evidence base for the development of a statewide paediatric palliative care service.

## **The following key findings were identified:**

1. Children with life-threatening and/or progressive illnesses prefer to remain at home for care whenever possible.
2. Many families are significantly affected physically, emotionally, mentally and financially.
3. Parents need ongoing multidisciplinary support from PMH throughout the trajectory of their child's illness.
4. Parents require specific assistance regarding the provision of care, including aids and equipment, appropriate nutrition and pain management for their sick children.
5. Home visits by health professionals are required by families of children requiring palliative care, especially to discuss management of nutrition and pain.
6. Professional carers providing in-home and residential respite care must be skilled in the care of such children.
7. Parents require clear, straightforward information about their child's condition, treatment and long term outcome.
8. Parents require education and practical assistance with caring for their other children.
9. Siblings of sick children have specific needs and are sometimes burdened with the care of their brother/sister.
10. Parents use and require access to a wide range of community education and resources.
11. Families of children who require end-of-life care prefer that care be provided in the home.
12. Families of children with chronic life-threatening illnesses/or disabilities require access to both in-home and residential respite care.
13. There is a need to improve current levels of in-home and residential respite care services.
14. Professional carers providing end-life-home care require specific paediatric knowledge and experience, particularly regarding medication dosages and administration.
15. Some parents of children with non-oncology conditions would use a dedicated children's respite centre.
16. Improved coordination between community-based disability services with service providers and families is required. There is a need for increased leadership to organise inter-agency collaboration, and for a case management approach for families.
17. The eligibility criteria for accessing support (e.g. respite, aids and equipment, allied health care, home care) are narrow and inconsistent.
18. There are a number of access and travel issues related to inadequate parking, limited public transport and ACROD bays at PMH and in the community.
19. There is a lack of recognition of the caring role, with many families feeling isolated and "battling on".

There is a clear and pressing need for the development of an integrated statewide paediatric palliative and supportive care service model of care in which cure-directed treatment and palliative care are integrated, allowing the child to benefit from both philosophies of care. In light of recent recommendations from the Report of the Health Care Reform – A Healthy Future for Western Australians (2004) and the National Palliative Care Strategy (2000), the emphasis should be on: the implementation of coordinated and evidence-based clinical guidelines for the care of children with complex and chronic conditions, provision of palliative and supportive care facilities for all categories of patients (inpatient, day patient and ambulatory), and infrastructure support for the provision of quality and effective palliative care through partnerships between those individuals who are dying, their families and health professionals.



# Recommendations

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## CORE ELEMENTS IDENTIFIED FOR CONSIDERATION IN THE FUTURE DEVELOPMENT OF AN INTEGRATED PALLIATIVE AND SUPPORTIVE CARE SERVICE IN WESTERN AUSTRALIA

Results from this study have led to the identification of a model of care for a statewide paediatric palliative and supportive care service that is based upon two key principles:

- ❖ **Care must be community based**, linked and integrated with Princess Margaret Hospital in collaboration with other community services such as Disability Services Commission, Silver Chain and Lady Lawley Cottage.
- ❖ **Care must be coordinated** by a full multidisciplinary team in consultation with the children and their families.

The model must incorporate the following core elements:

1. Simple and accessible home-based care for all families of Western Australia.
2. Care that is individualised and responsive to parents' needs.
3. Care that is coordinated by a full multidisciplinary team.
4. More inclusive criteria for access to support services.
5. Access to flexible and responsive respite support.
6. Plans for long term care support.
7. Caters for end-of-life care.
8. Specific designated respite beds.
9. Need for specialised respite services for children with non-oncology diseases (home and special facilities).
10. Coordination between existing community-based disability services (in terms of palliative and supportive care for children), service providers and families (i.e. a need for broader criteria to accommodate the needs of children and their families, a need for increased leadership to organise inter-agency collaboration, and a need for a case management approach by families).

Empirical findings from this study provide specific guidelines for the broad delivery of palliative and supportive care for children suffering from life threatening or chronic illnesses/disabilities with complex care needs. Appropriate infrastructure support is required to facilitate the provision of quality and effective supportive and palliative care through partnerships between sick children, their families and health professionals.

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# Notes

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