



Paediatric Palliative Care Service Model Review

Final Report | January 2004



THE NATIONAL
PALLIATIVE CARE PROGRAM



Prepared for the Australian Government
Department of Health and Ageing
by Healthcare Management Advisors Pty Ltd

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Paediatric Palliative Care Service Model Review — Final Report prepared by Healthcare Management Advisors Pty Ltd, PO Box 10086 Gouger Street, Adelaide SA 5000, 1st Floor, 65 Henley Beach Road, Mile End SA 5031, phone: (08) 8150 5555

Contents



EXECUTIVE SUMMARY	1
Project outline	1
Survey results	2
Analysing the results	4
Strategies for improvement	8
Conclusion	11
1 INTRODUCTION	13
2 METHODOLOGY	15
Situation analysis	15
National survey of palliative care service providers	15
Case studies	16
Consumer interviews	16
National Paediatric Palliative Care Workshop	17
3 INTERNATIONAL TRENDS IN PAEDIATRIC PALLIATIVE CARE	18
Literature review methodology	18
Definition of paediatric palliative care	19
Population characteristics	19
Health professionals in paediatric palliative care	20
Paediatric palliative care services	21
Summary of literature review findings	28
4 PAEDIATRIC PALLIATIVE CARE SURVEY ANALYSIS	30
Structure of survey form and process	30
Survey summary statistics	31
Profile of service providers	32
Profile of registered paediatric palliative care clients	39
Costs of providing paediatric palliative care services	42
Ability to meet client needs	52
Conclusion	54
5 CASE STUDY REVIEW	56
Case study review objectives	56
Case study sample	56
Case study framework	57
Discussion framework	57

Summary of current paediatric palliative care models	59
Variations in service delivery	73
Gaps in service delivery	74
Barriers to effective service delivery	75
Evidence-based best practice	78
6 CONSUMER NEEDS ANALYSIS	81
Profile of selected consumer participants	81
Participants' experiences of diagnosis	81
Participants' experiences of using services	86
Services that were lacking	90
Perceptions of paediatric palliative care	91
Caring for the child at home	92
The child's death	95
Grief and bereavement	96
Summary of findings	97
7 BEST PRACTICE MODELS OF PAEDIATRIC PALLIATIVE CARE	104
Issues unique to providing paediatric palliative care	104
Conceptual features of a best practice paediatric palliative care model	104
8 PROPOSED STRATEGIES FOR IMPROVEMENT	111
1 Establishing a national paediatric palliative care reference group	111
2 Developing national clinical practice guidelines and protocols	113
3 Improving the availability of information	114
4 Increasing resource allocations	115
5 Designating funding for approved research projects	117
6 Educating and training staff	119
7 Developing performance measurement mechanisms	121
8 Evaluating service improvement strategies	121
Conclusion	123
REFERENCES	125
APPENDIX A PALLIATIVE CARE SURVEY FORM	129
APPENDIX B SURVEY GUIDELINES	137
APPENDIX C INTERVIEW PARTICIPANTS	150

Executive summary



Project outline

Aims

Paediatric palliative care services aim to help both children with life-limiting conditions and their families in the knowledge that, while no medical cure may be available, a significant contribution can still be made to the children's and families' quality of life at this extremely difficult time.

In 2002, the Australian Government Department of Health and Ageing appointed Healthcare Management Advisors (HMA) to undertake a national project to:

- review models of paediatric palliative care across different life-limiting illnesses, families and communities, taking into account cultural and geographical differences;
- identify the service models that best meet the palliative care needs of dying children and their families; and
- identify areas that have potential for development.

Approach

The project had several elements:

- wide consultation with stakeholders to analyse the current issues affecting the provision of paediatric palliative care internationally and in Australia;
- a national survey of palliative care providers to create a comprehensive database of services provided and their characteristics;
- a comprehensive literature review;
- 15 case studies of a cross-section of palliative care providers across Australia to collect information about how paediatric palliative care providers operate, what affects their services and how their services could be improved;
- interviews with 20 recently bereaved families to gather their views about their experiences and needs; and
- a national paediatric palliative care workshop.

This review found that, as in other developed countries, the needs of dying children have not been addressed to the same extent as the needs of dying older patients. In part, this is because of the comparatively small demand for paediatric palliative care and the difficulties in differentiating between active treatment and palliative care in children and adolescents.

Survey results

Agencies providing paediatric palliative care

All Australian palliative care service providers who provided services to registered clients during 2001–2002 — a total of 364 services — were surveyed. Of those 364 agencies, 253 (or just under 70%) responded to the survey, and 111 agencies did not provide data.

Of the 253 responding agencies, 125 agencies (or just under 50%) said they had the capacity to provide paediatric palliative care services. However, only 74 of those actually provided that kind of service in 2001–2002. The remainder of the 253 (128 agencies) said they provided palliative care only for adults. Of those agencies that indicated that they did provide paediatric palliative care services, 22 (17.6%) were unable to provide details relating to the costs of their services.

Types of services provided

Agencies were asked about the types of paediatric palliative care they provided. Their answers suggested that, of all the services provided, about 40% were associated with giving emotional support, community-based care, symptom control and information. The survey data also demonstrate the limited availability of bereavement support (9%), respite care (6%) and sibling support (4%).

Staff

The survey asked agencies about the kinds of staff employed to provide paediatric palliative care services at 30 June 2002. The results showed that:

- registered nurses represented 44% of the total staff employed,
- only 1.6% of nurses had a paediatric palliative care qualification, and
- medical practitioners represented 9.3% of the total workforce, including palliative care physicians (5.3%) and general practitioners (1.6%).

The results indicated that additional resources were required to employ qualified paediatric palliative care medical and nursing staff, mental health workers, psychologists and pastoral care staff to provide more comprehensive palliative care.

Client conditions

Agencies were asked what types of conditions their 2001–2002 paediatric palliative care clients had. The five client condition categories used for the survey were:

- conditions for which curative treatments have failed, such as cancers;
- conditions for which intensive treatment may prolong and enhance life, but because of which premature death still occurs, such as cystic fibrosis;
- progressive diseases for which treatment is exclusively palliative, but may extend over many years, such as that for Batten's disease;
- conditions, such as severe cerebral palsy, in which neurological problems lead to increased susceptibility to complications and premature death; and
- other conditions, where patients are undergoing continuing curative treatment.

Significant results were that:

- Victoria and New South Wales had the largest proportions of clients registered for all five treatment conditions;
- Victoria and New South Wales provided significant support to families while the children were still undergoing curative treatment; and
- Very Special Kids in Victoria was the only agency that provided a formal bereavement program for families.

Estimated costs

The results of the survey analysis show the high unit costs of providing paediatric palliative care services, and so support the findings of a number of other research studies. The most important points the data showed were:

- at the national level, the average estimated cost of providing palliative care services to a client was \$3,577, while the average cost of providing paediatric palliative care to a client was significantly higher, at \$4,998, representing a 40% higher utilisation of resources; and
- the average cost of paediatric palliative care ranged from \$10,951 per client in New South Wales to \$1,950 per client in the ACT.

Resources used

Agencies were asked about the proportion of resources they used in providing palliative care services during 2001–2002. These proportions were used to estimate the cost of providing services for each of 14 types of service. The most important information gathered from the analysis of these data is shown below.

- The highest proportion of national resources (31.5%) was used in providing hospice services in New South Wales, Victoria and Queensland.
- A total of 29.5% of national resources was used to provide respite care, with New South Wales and Victoria reporting the highest expenditure in this area.
- The proportions of national resources associated with providing bereavement care (3.7%), and emotional (3.7%) and sibling support (0.9%) were significantly lower than for other types of care. These findings are similar to those of other studies undertaken in the United Kingdom and the United States of America.

Meeting clients' needs

The survey asked paediatric palliative care agencies to assess the extent to which they were able to meet the needs of their clients. The results showed these main points.

- 16.8% of agencies said that they were able to meet their clients' needs, while the vast majority (65.6%) indicated that the needs of clients were only being partially met, 3.2% of agencies reported that they were unable to meet client needs, and 14.4% of agencies did not answer the question.
- A review of the results of this analysis on a state-by-state basis shows that, apart from the ACT, the proportion of agencies that were able to meet all their clients' needs is low and ranged from 50% of agencies in Queensland to 4.3% of agencies in New South Wales.

These results suggest that additional resources are required to improve the availability of paediatric palliative care services.

Reasons clients' needs were not met

The survey analysed the reasons that service providers were not able to meet the needs of their clients, by service catchment area. The results are summarised below.

- At the national level, 24.8% of all respondents, 53.6% of which were local providers, were unable to meet clients' needs because of low client referral numbers, which meant that staff lacked experience and skills in providing specialist paediatric palliative care. Other reasons cited included the remoteness of the location of clients (11.5%), having to access services through other organisations, which indicates problems with service coordination (16.8%), and lack of resources (14.2%).
- Of the 40.7% of agencies who provided regional services, the problems of unmet need were attributed to lack of education or training, the geographic isolation of clients, lack of professional support and lack of experience because referral numbers were low.
- The reasons that specialist children's hospitals (7.1%), responsible for providing statewide services, could not meet clients' needs were a lack of resources and a lack of professional support staff.
- Other services (8%), such as local government, reported that the reasons they could not meet need were associated with accessing services through other organisations and low numbers of client referrals.

The survey analysis suggests that an evidence-based best practice framework is required to support the provision of competent clinical services across the continuum of care. The project's literature review showed that a number of countries have addressed this issue by developing nationally agreed protocols that focus on coordination, continuity of care and providing support and information to service providers.

Analysing the results

International models of paediatric palliative care

The project's literature review identified a number of models of paediatric palliative care, and found that no one model would necessarily meet the needs of all families. The key issues identified by the project with regard to models are outlined below.

- **Referral** The question of when to commence palliative services was seen to be problematic. In Australia, the stakeholders consulted expressed a view that palliative services should be considered for all children living with a life-threatening condition.
- **Preference for home-based care** While home-based care was seen as a desirable service, it was considered that families should have a choice of home or another external facility (hospital or hospice) for the purposes of receiving palliative care. Families should have the appropriate level of clinical support to meet their needs no matter which they choose.
- **Communication** Communication between health professionals and families was considered to be vital to successful palliative care, with families citing good information as one of their highest priorities.

- **Emotional and social support** Those interviewed for this project thought this was a very important part of palliative care. The needs of siblings were also considered an important part of the care planning process.
- **Education and training of staff** It was considered essential that education programs were available for staff caring for dying children and their families, to help staff understand the emotional reactions of children receiving palliative care and those of their families.
- **Family advocacy** The research literature has shown that paediatric palliative care is increasingly focusing on the needs and wishes of the children and families receiving care. This has been evident in the many attempts made to ascertain clearly what families need and want from services.

Models of care currently used in Australia

No one model of care suits all situations in Australia. The following is a summary of the key features of models of care currently used in Australia, based on the models used by the project's 15 case study sites, and the reasons they vary so much.

- **Demand** More comprehensive models of care have emerged as a result of statewide consultation or liaison, or where there is a significant demand at the local level (for example, from specialist paediatric hospitals). Where the demand for paediatric services is low, agencies tend to incorporate them in adult palliative care programs.
- **Complexity and prognosis of conditions** One of the main reasons there are so many different models of care is the significant variability in the complexity and prognosis of life-threatening conditions.
- **Differing choices** Most families prefer their children to die at home, but some families do not have the physical and emotional resources to care for them at home. They may opt to place their children in hospital at the end stage of life, so it is important to ensure that appropriate facilities are available.
- **Range of service providers** Palliative care services are provided by multidisciplinary teams at specialist children's hospitals, general hospitals, designated children's hospice facilities and community-based agencies. Services can be provided at home or in the facility. In addition, respite care for the parents and siblings, and in some cases comprehensive bereavement programs, are available for the whole family. Each of these service providers is bound by its own internal service delivery protocol.
- **Variations in availability** There are significant differences in the availability of paediatric palliative care services to families, and these are largely determined by the demand for these resources. There are not enough social support services for children and families, including respite care and bereavement, emotional, spiritual and sibling support programs. Similarly, there is not enough psychosocial and bereavement support for health care professionals who provide these services.
- **Education and training of staff** There were very few service providers who had tertiary training in, or attempted to focus on, paediatric palliative care, and there are limited educational opportunities in this area. To compensate for this lack of training, a number of states have implemented training programs for health professionals.

Family related issues

Our interviews with the 20 families who had received paediatric palliative care services indicated that some families found services haphazard and erratic, some found them sensitive, responsive and valuable, and others found them to be unavailable or lacking in care and compassion.

Areas where services performed well

- Families appreciated services that were coordinated and cooperative, as this eradicated many of the problems experienced by those unfortunate enough to have to ‘fight for services’ or ‘tell the same story’ to a range of different service providers who seemed unable to communicate with each other.
- Families especially valued services where a skilled, knowledgeable and caring key worker or case manager was available to help them and who was introduced as early as possible. Some mentioned the paediatric palliative care nurse in this respect.
- Other services which families valued were support organisations, where they could often talk with other parents, carers and children who had had similar experiences.

Areas where services performed badly

- Centrelink and the benefits system were consistently cited as particularly difficult and inflexible services to access and benefit from.
- Diagnostic services and the process of diagnosis were clearly contentious for many parents and carers, as the professionals charged with either testing the child or breaking the news were often insensitive.
- Some families experienced difficulties with the hospital system generally, feeling that it was not ‘conceptually attuned’ to the needs of a child with a life-limiting illness.
- Where families said their needs were not met, many had suggestions about services that they would like to see in place. For example, they wanted an integrated, user-friendly, cooperative, interdisciplinary, flexible, compassionate service, not a fragmented, labyrinthine collection of different services that did not ‘speak to each other’ and were difficult to find, access and use.

Areas where no services were available

Families found several necessary services currently unavailable or difficult to access.

- Support services for fathers and siblings were considered the most pressing issue. While valuable assistance was provided by support and peer organisations, statutory paediatric palliative care services rarely catered for their needs.
- Rural families in this study acknowledged that living in a rural area aggravated many of the problems associated with accessibility, costs, travel, home life disruption and so on.

Information

Families were conscious of the distinction between being given information, knowing what that information contained, and understanding it.

- Families required information when there were indications that something was not well with their children, about the children’s treatment and management, and about how this was going to affect their lives.
- Many families routinely used the internet to gain information that would until recently have been relatively unobtainable. This resource is also helping families share information about treatments, programs and all aspects of the children’s illnesses with other families in online support groups.
- Specific information was required about dealing with death, as often people found it difficult to tell families directly, clearly and sensitively what the death of their children would be like and what they could do at this time.

- For many parents and carers in this study, the most valuable information was usually obtained by word of mouth from either respected palliative care staff or from other parents or support organisations who had experienced similar situations.

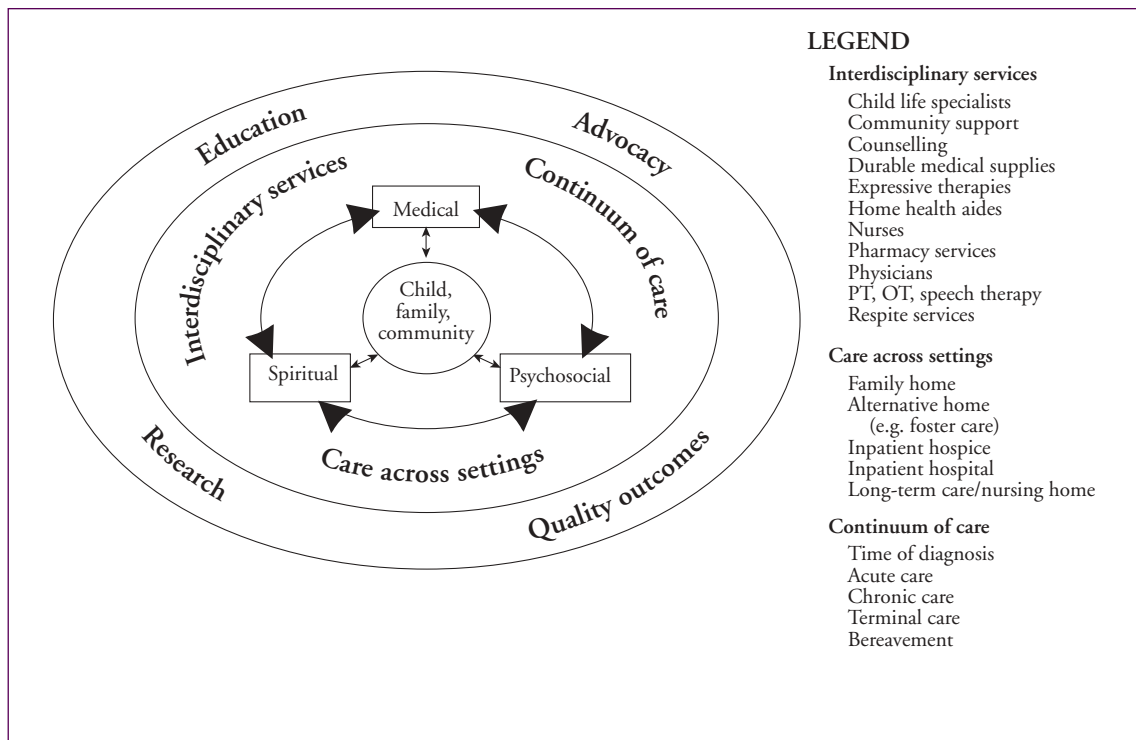
Features of a best practice model

There is now a growing global emphasis on implementing improved models of care that provide for an accessible, integrated, interdisciplinary approach based on principles such as:

- respect for the dignity of patients and their families,
- access to competent and compassionate palliative care,
- support for the caregivers,
- improved professional and social support for paediatric palliative care, and
- continued improvement of paediatric palliative care through research and education (Preboth 2001, p 569).

The project's literature review identified an ideal conceptual model for providing paediatric palliative care that is schematically presented below. This model focuses on meeting the needs of children, families and communities by integrating all aspects of care under unified goals, and offering interdisciplinary, holistic services. Best practice models of care are currently moving away from a rigid demarcation between curative and palliative care and are capitalising on the natural synergy that can exist between them.

PROPOSED PAEDIATRIC PALLIATIVE CARE MODEL



Source: ChIPPS 2001.

At the centre of this model are the needs of the child, family and the community. The care is delivered at home, in a community-based facility or in a hospital. Key elements of the program are tailored to meet the needs of the child and family, with packages of care being added or removed according to changes in the child's condition. There is no single care delivery model that will work across all communities. Instead, the model should take into account the availability of existing resources and programs, avoid duplicating services, and build on what is currently available.

Strategies for improvement

The project has suggested a number of strategies to achieve ongoing improvement in paediatric palliative care services in Australia. The success of these initiatives will rely on all stakeholders taking an active role in putting them into practice.

A national paediatric palliative care reference group

Currently in Australia, each state or territory is responsible for providing paediatric palliative care, and services are usually provided under the auspices of each palliative care program. We believe it is important to establish a national forum to develop evidence-based national definitions, standards and policies that can address a range of issues affecting the delivery of paediatric palliative care.

Strategy

We propose a national paediatric palliative care reference group (PPCRG) be established to develop the evidence-based national definitions, standards and policies required to implement integrated service models, and develop information, education and research strategies to improve the delivery of paediatric palliative care. This would ensure a national integrated approach to delivering paediatric palliative care, and would enable the best use of research by ensuring that new evidence is used promptly and effectively.

National clinical practice guidelines and protocols

Achieving the paradigm shift required to implement improved and integrated family-centred models of paediatric care will require the collaboration of many stakeholders. Such a collaboration should develop and implement clinical practice guidelines and procedures for palliative, end-of-life and bereavement care that meet the needs of children and families.

Strategy

We propose that the PPCRG be responsible for developing and promulgating national guidelines and protocols for paediatric palliative care services.

Information

Comprehensive and timely information about both clinical and management aspects of paediatric palliative care is required to:

- provide support to families (particularly in rural areas), local health care professionals, community hospitals and other relevant organisations through internet, telemedicine and telephone consultative services;
- monitor outcomes;

- improve service delivery; and
- undertake research.

Strategy

Achieving improvements in the availability of information will require the collaboration of all stakeholders in developing information programs and other resources that will help families and clinicians by:

- supporting an integrated family-centred model of paediatric palliative care (local health care providers need advice about aspects of care, families need information to help them advocate for appropriate care, and health professionals information to help them provide high quality, coordinated care); and
- developing a national paediatric palliative care database (to redress the lack of clinical and management information required to improve service delivery). Consideration should be given to developing a national paediatric palliative care information system that collects and reports data about these services over the next five years.

More resources

Our review revealed that, at present, insufficient funding is available to meet the needs of children with life-threatening conditions and their families. This has resulted in significant shortfalls in some services. Additional funding is also required to support teaching, training and research programs.

Strategies

We propose that:

- the Australian Government Department of Health and Ageing adapts state health agreements to encourage the allocation of specific funding to paediatric palliative care;
- individual state health jurisdictions consider allocating specific funding to paediatric palliative care on a rational and equitable basis that recognises the need for integrated statewide services, the increasing demand for these services and the level of unmet need.

Designated funding for approved research projects

There were a number of significant shortfalls in services' capacity to meet the needs of clients. We also found that there were significantly more resources available to children with malignant conditions than to those with other conditions, because of the support provided by private fundraising. Resources must be made available to support approved projects aimed at researching the shortfalls, to ensure that these gaps are addressed. These projects could include clinical, behavioural, policy, organisational and educational research.

Strategy

We propose the following areas of research as national priorities:

- protocols for bereavement support;
- culturally sensitive services for key communities that will take into consideration issues of language, culture and spiritual beliefs; and
- additional respite care facilities that will allow flexibility and family choice.

Education and training of staff

Our review has shown that few health care professionals are trained in providing specialised palliative, end-of-life and bereavement care to children and their families. To achieve an integrated service model, additional resources are required to educate and train staff involved in providing paediatric palliative care in community-based agencies.

Strategies

We propose:

- the introduction of paediatric palliative care modules to tertiary education;
- the introduction of paediatric palliative care fellowships and training opportunities;
- the identification of staff interested in paediatric palliative care, who will act as leaders in the field;
- the provision of training for paediatric palliative care volunteers and caregivers;
- the allocation of specific funding for training and education;
- the provision of training for counsellors, psychologists and teachers;
- the establishment of specialists as clinical role models for other professionals, through the PPCRG;
- the creation of strategies to evaluate educational techniques in palliative, end-of-life and bereavement care; and
- the allocation of resources to develop and implement innovative training programs.

Performance measurement

Ongoing nationally agreed performance measurement mechanisms are required — clinical indicators founded on evidence-based best practice. Currently in Australia, performance measurement focuses on undertaking consumer satisfaction surveys and reviewing the way a service manages a condition, analysing the results, and then altering practices to take into account adverse findings or omissions.

Strategy

We propose an examination be undertaken of current practice with regard to unacceptable variations in treatment, as well as of clinical and cost effectiveness, to identify any serious or persistent clinical problems. We believe there is a role for the PPCRG in this examination, to build on the work that has been done in Australia and overseas in developing a national standard for measuring performance in accordance with evidence-based best practice.

Evaluation of service improvements

Program evaluation is an essential organisational practice in the health sector. However, it is not practised consistently, nor is it sufficiently well integrated into the day-to-day management of most programs. The PPCRG will also require evaluations of programs when making decisions about the future and to ensure that the strategies that have been developed and implemented have performed effectively.

Strategy

To ensure that the national paediatric palliative care program remains relevant and that there is progress in implementing the agreed service improvement strategies, progress must be monitored. One of the PPCRG's key focuses should be establishing a broad framework through which the impact of the projects undertaken can be evaluated

Conclusion

We have proposed a number of reinforcing strategies that address the multidimensional problems affecting the provision of paediatric palliative care services in Australia. They provide for integrated structural reform, changes to resource allocation, improvements to the social support for children and families through evidence-based research projects, education and training for staff and program evaluation. We believe this report will present many challenges to the Australian health sector. It will require an ongoing collaborative effort between national and state governments, individual service providers and the families who care for children with life-threatening conditions to systematically improve palliative care services.

Chapter 1

Introduction



The National Palliative Care Strategy (DHAC 2000) represents the commitment of the Australian, state and territory governments, palliative care service providers and community-based organisations to the development and implementation of palliative care policies, strategies and services that are consistent across Australia, and to the delivery of quality palliative care that is accessible to all people who are dying. Objective 2.4 of the strategy seeks to promote 'ongoing evaluation and research into client care needs, best practice palliative care, service delivery models, and resource allocation models, and to implement the results of such research' (DHAC 2000, p 18).

In undertaking this project, the Australian Government Department of Health and Ageing (DHA) established a steering committee to act as an advisory body for the consultants undertaking this research project. The terms of reference of the steering committee were:

- to provide guidance on key issues about conducting the project, with a specific emphasis on the feasibility of the work to be undertaken;
- to provide technical advice on conducting the review, including on the design of the national survey for palliative care service providers and the focus of the family interviews; and
- to advise on ways to assess the efficacy of the project and the utility of the results.

The steering committee was comprised of representatives of the DHA Special Projects Branch and state representatives of the Intergovernmental Palliative Care Forum and included:

Rita Evans	Director, Rural Health and Palliative Care Branch, DHA
Leane Watt	Project Officer, Rural Health and Palliative Care Branch, DHA
Katy Robinson	Project Officer, Rural Health and Palliative Care Branch, DHA
Meryl Horsell	Senior Project Officer, Department of Human Services, South Australia
Ruth Foley	Purchasing Manager, Department of Health Western Australia
Fiona McAlinden	Manager, Services Development, Very Special Kids, Victoria

In modern society, the death of children is relatively rare because of the advent of antibiotics, immunisation and treatments for malignancies (Hynson and Sawyer 2001). Accordingly, paediatric palliative care is a significantly different area to adult palliative care (Hynson and Sawyer 2001; Mallison and Jones 2000; Goldman 1998) and one in which the most suitable approaches to care are still being developed (Goldman 1998). This project presents an important and timely opportunity to contribute to the development of paediatric palliative care services in Australia.

Developing and implementing improved service delivery models while providing evidence-based, best practice paediatric palliative care will require a significant commitment from federal, state and territory

governments to considering a range of issues affecting the way palliative and end-of-life care is provided to children and their families. This study is the first step for Australia in addressing these issues from a national perspective: it will identify initiatives to transform palliative and end-of-life care across the country, ensuring the needs of children with life-limiting conditions and their families are met.

The Australian Government Department of Health and Ageing appointed Healthcare Management Advisors (HMA) to:

- review models of paediatric palliative care across different life-limiting illnesses, families and communities, taking into account cultural and geographical differences;
- identify the service models that best meet the palliative care needs of dying children and their families; and
- identify areas with potential for development.

The project commenced in February 2002, following acceptance of the project plan by the steering committee on 31 January 2002.

In order to gain the quantitative and qualitative information required, we, the authors, have collected a comprehensive range of information and views about a sample of current services, providing a rich base from which to identify the characteristics of models which best meet the needs of dying children and their families.

This document presents the key findings of our national review of paediatric palliative care services. It addresses the study's requirements by identifying service models that may better meet the palliative care needs of dying children and their families, and potential opportunities for improving service delivery. Because of the comprehensiveness of the data collected, many issues were also raised that can be further investigated. This report contains a small subset of the information gathered and the issues raised while we were focusing on the key questions posed in the project brief.

Chapter 2

Methodology



This chapter briefly sets out the methodology for each of the major components of the project. The intent is not to describe the methodology in detail (further details can be found in the appendices and relevant chapters), but to set out the main steps taken so that the resulting data can be considered in context.

Situation analysis

A literature review was undertaken and preliminary interviews were held with a broadly based group of paediatric palliative care stakeholders. A comprehensive overview of the current situation was submitted, and was subsequently revised on the basis of comments by the project steering committee in April 2002.

National survey of palliative care service providers

In August 2002, HMA conducted a national survey of 364 palliative care service providers to collect information to create a comprehensive database of services and their characteristics. These data included factors relating to organisational characteristics, approaches to services, client groups targeted, comparisons of community and hospital-based services, and so on. There were 253 survey forms received (a 70% response rate) and an analysis of these data was undertaken to develop a comprehensive profile of current paediatric palliative care services. Key steps in the development and administration of this survey were:

- 1 **Design survey questionnaire** Members of the HMA consulting team drafted a survey questionnaire in collaboration with the project steering committee. Through an iterative refinement process, the survey form and associated guidelines evolved to the point at which a pilot test was possible.
- 2 **Test survey questionnaire** The Women's and Children's Hospital in South Australia (the state's specialist paediatric hospital) agreed to test the survey form. The results of the test were generally very favourable and only a few minor changes to the form were made consequently.
- 3 **Identify palliative care service providers** Palliative Care Australia was asked to provide HMA with a list of all of its registered members who were palliative care providers. A review of this list showed that a number of organisations were not included (such as state specialist paediatric hospitals), and these were added. The rationale for including all palliative care agencies (adult and paediatric) was to ensure that data was collected from adult service providers who also provided services to children.
- 4 **Print and distribute surveys and guidelines** A package containing the survey form and guidelines was distributed to all palliative care agencies in Australia (copies of these documents are contained in appendixes A and B).
- 5 **Survey administration** HMA consultants provided a telephone inquiry service throughout the course of the survey. Incoming data was checked for quality and completeness and, wherever possible, issues were followed up with the relevant agency representatives. All responses on the forms were coded as necessary and the data were entered into a purpose-designed database.

6 **Data analysis** The data were analysed to provide a composite overview of the status of paediatric palliative care service across Australia. The results were then used to identify the 15 agencies on which case studies were based.

Case studies

Based on the analysis of survey data, 15 case study sites were selected (located in metropolitan and rural areas). We, the authors, designed a case study framework and used this as the basis for our consultations with a range of stakeholders at each site to gain a comprehensive understanding of the operation of services. This process provided us with more detailed information about the structure and operation of services, the theoretical or evidence base for the approach, issues that affected service delivery and views about barriers to, and opportunities for improving, services.

The information collected as part of the case study process enhanced our interpretation of the survey data and allowed us to focus on services that were thought to be exemplars of good or best practice. A report of the 15 case studies is provided in chapter 5.

Consumer interviews

As part of this project, we conducted interviews in January 2003 with 20 bereaved families residing in metropolitan and rural areas of New South Wales, Victoria and South Australia. The objective of these interviews was to gain the perspectives of families who have received paediatric palliative care services on their experiences and needs while they were accessing these services.

Approach to conducting the consumer interviews

The palliative care services of the Children's Hospital at Westmead in New South Wales, Very Special Kids in Victoria, and the Women's and Children's Hospital in South Australia were invited to provide a list of bereaved families whose children had died over 12 months ago who resided in both metropolitan and rural areas in those states.

After obtaining approval from their ethics committees, the hospitals made an initial approach to the families in their respective states, to ascertain if they were willing to participate in the interview process. The names of 20 families who were willing to be interviewed were subsequently provided to the research team, who made contact with each family to schedule an appropriate time for the interview and provide additional information relating to the study (appendix C provides an anonymous description and list of interview participants).

After a consent form was signed by the family participant, the interviews were conducted at the families' homes or their location of choice, and these lasted between one and three hours each. These interviews were arranged and conducted by two experienced nurses with paediatric and mental health backgrounds, and were akin to natural, informal conversations that allowed the participants to speak freely about their most salient experiences and perceptions regarding their child's life and death. That there was no prescriptive interview schedule as a measure of interpretive 'openness' was considered to be essential.

However, the families were clearly informed as to the purpose of the interviews, which was to ascertain their experiences and perceptions of their child's care and in particular, the care around the time of their child's dying. As part of the careful explanation of the research given, participants were assured that they could choose not to discuss any issue or to stop an interview at any time and for any reason.

Interviews usually began with an open but focused question which asked the participants to take their time, start at a point in their child's life that they were comfortable with, and 'tell the child's story' at their own pace and in their own words. For most participants, this meant starting at the point when they first noticed that something was wrong with their child. The interviews were unobtrusively tape recorded with the participants' permission, then they were transcribed verbatim and double-checked to ensure the accuracy and completeness of the interview data. Unfortunately, a recording problem during one of the interviews rendered the interview tape untranscribable and so the data set for the consumer interviews section comprises 19 interviews.

This information was an important consideration in assessing the extent to which current service models met consumer needs. Data from each of the interviews was analysed and a report was prepared that is presented in chapter 6 of this report.

Analysis of the consumer interviews

The analysis method adopted for this qualitative research study was 'thematic analysis'. In this approach, the interviews were each entered into a qualitative data management software package called QSR N-vivo. Each interview was then read and 'coded' to highlight particularly salient and important aspects of the participants' experiences, perceptions, thoughts, feelings and activities. This approach involved building individual coded segments of interview data thematically into a bigger picture, which illuminated the participants' experiences of their child's palliative care. The thematic building was also guided by the aims of the project and therefore encompassed both participants' responses to the identified areas of interest and some other experiences that may not have been specifically identified at the outset, but which were nevertheless found to be important.

National Paediatric Palliative Care Workshop

A component of our methodology also involved conducting a national workshop on 20 June 2003, in Sydney, with invited representatives of the 15 case study sites. The objective of this workshop was to present our review findings and to seek stakeholder input into the formulation of options for:

- identifying the service models that best meet the palliative care needs of dying children and their families, and
- identifying areas that may be developed in the future.

Chapter 3

International trends in paediatric palliative care



This chapter outlines the results of our review of national and international literature about paediatric palliative care services.

Literature review methodology

The literature review was conducted by members of the HMA team in consultation with our specialist clinical advisers. The literature search encompassed both peer-reviewed journals and other published literature. Electronic database searching, communication with Australian experts in the field, hand-searching of conference proceedings, along with internet searches targeting individual organisations and government websites were among the key approaches used to identify literature relevant to this study. The literature search methodology incorporated the following elements:

- 1 **Electronic database searches** Subject and text words were used in searching databases, with English language limits and a publication date after 1980 being applied.
- 2 **Internet searches** Key organisation and government websites were searched. Free text internet searches were also undertaken, using the Google search engine.
- 3 **Reference lists** Reference lists of key journal articles were scanned to identify further studies of interest (see those listed in the references section at the end of this report).
- 4 **Consultation with specialist clinical advisers** Our team of specialist clinical advisers was able to identify, through previous research and consultation with colleagues, additional articles and reports relevant to the study.

The literature on paediatric palliative care is diverse and growing. A frequently voiced criticism of the early literature related to palliative care was the relative invisibility of children in the face of the reality that children do die. Recently, however, the paediatric palliative care field has grown and developed to the extent that there is now a fairly wide body of research and practice-based literature devoted to most aspects of palliative care for children (for example, policy issues, ethics, clinical practice, program evaluation and research approaches).

Nevertheless, it is evident that adult palliative care services have developed more comprehensively than palliative care services for children. Previous research has shown, however, that while almost all bereavement is painful, the loss of a child is especially traumatic for parents (Rando 1986, Arnold and Gemma 1994, Jacob and Scandrett-Hibdon 1994). Palliative care organisations, such as the International Work Group on Death, Dying, and Bereavement (IWGDDB 1993), have been clear in their assertion of the importance of comprehensive palliative care services for all children and their families.

Paediatric palliative care services developed to help both the children and their families are premised on the knowledge that, while no medical cure may be available, there is still a significant contribution to be

made to the quality of life of the children and their families at this extremely difficult time. In this review, we depict the landscape of paediatric palliative care by describing the issues involved in defining the term, understanding the characteristics of the children and families who may require this service, and exploring the nature of some of the services available. This work sets the scene for our review of the substantive areas of:

- trends in developing and providing paediatric palliative care services;
- models of care used for delivering paediatric palliative care services;
- guidelines for delivering paediatric palliative care services;
- evaluation studies of the effectiveness of paediatric palliative care service models, including any information on the resource allocation approaches and costs associated with the model; and
- process, output and outcome indicators used in developing, managing and evaluating paediatric palliative care programs.

Definition of paediatric palliative care

One of the immediate difficulties in exploring this area is that the term ‘palliative care’ is problematic. The Royal College of Paediatrics and Child Health (UK) has defined paediatric palliative care as an active and total approach to care for children and young people with life-limiting conditions, which embraces physical, emotional, social and spiritual elements, focuses on enhancing the quality of life of the children and providing support for the families, and includes managing distressing symptoms, providing respite care and care through death and bereavement (RCPCH 1997). The IWGDDB (1993) argued that a paediatric palliative care service should be

An individualised, coordinated system of health care which provides continuity of services between the hospital, the home and the community [which] must be developed as soon as feasible after diagnosis.

and that

This coordinated system must be maintained throughout the illness and death, with follow-up support for family members after death. It is mandatory that this system of care be made accessible to all children and their families regardless of race, sex, culture and/or ability to pay. The system of care must be flexible in providing services in the community, the home, and the hospital.

Our literature research findings have indicated that consideration should be given to adopting and operationalising a more holistic definition of paediatric palliative care.

Population characteristics

Hynson and Sawyer (2001) noted that accurate data regarding the number of children and adolescents requiring palliative care are not available in Australia. Nevertheless, Goldman (1998) estimated that, in the UK, in a health district of 250,000 people with approximately 50,000 children 0–19 years of age, five children are likely to die from a life-limiting illness each year and a further 50 will have a life-limiting illness, of which half will need palliative care at any time. Based on these estimates, there are approximately 20,000 children suffering from life-limiting conditions in the UK, many of whom will

not live to reach adulthood. Despite the fact that Australia has a slightly larger proportion of the population in this age range (21.3% as against 19.6%) (ABS 2000), applying the same fractions suggests there are approximately 3,832 children and adolescents with a life-limiting illness in Australia, of which half will require palliative care.

Palliative Care Australia (PCA 1998a) found that 85% of those receiving palliative care are over 55 years of age and that fewer than 10% of those patients have a diagnosis of other than malignancies. Interestingly, tables in the 1998 national census of palliative care services (PCA 1998a) do not mention children and adolescents as a population of specific interest and analysis does not go beyond consideration of those over 55 years of age. This is perhaps a reflection of the relative rarity of deaths of children and adolescents, and in turn supports the suggestion that paediatric palliative care is an underdeveloped area (Baum et al 1997; Darbyshire, Haller and Flemings 1997; Frager 1997; Roy 1997; Cooley et al 2000; AAP 2000; Hynson and Sawyer 2001; Levetown 2001; Rushton and Catlin 2002).

While the majority of adult palliative care patients are suffering from a malignancy (PCA 1998a), Goldman (1998) estimates that 60% of paediatric palliative care patients are suffering from other life-limiting conditions. To classify conditions for the purposes of developing appropriate palliative care responses, both Goldman (1998) and Hynson and Sawyer (2001) proposed four patterns of disease progression:

- conditions for which curative treatments have failed, such as cancers;
- conditions for which intensive treatment may prolong and enhance life, but because of which premature death still occurs, such as cystic fibrosis;
- progressive diseases for which treatment is exclusively palliative, but may extend over many years, such as that for Batten's disease; and
- conditions, such as severe cerebral palsy, in which severe neurological problems, although not progressive, lead to vulnerability and increased susceptibility to complications and premature death.

Accordingly, the range and timing of services required by children living with a life-limiting condition and their families varies considerably. The initiation of palliative care is also a more complex issue for children and adolescents, as waiting for all curative avenues to be exhausted may delay referral to palliative care services, and discussion of palliative care may be seen as resignation to failure by parents or carers (AAP 2000).

The length of time between the onset or diagnosis of a life-limiting condition and the eventual death of a child or adolescent may see the child move through a range of developmental stages, increasing the complexity of this type of care.

Health professionals in paediatric palliative care

The literature findings indicate that an extensive range of professionals is involved in the care of children with life-limiting conditions. The relative rarity of death amongst children means that general practitioners may see only one or two cases during their careers and hospital paediatricians may see only one or two cases per year (Pinkerton 1993). Referrals to centres specialising in paediatric oncology, cystic fibrosis, cerebral palsy or degenerative neurological conditions move the focus of care away from local professionals. However, local professionals, despite their limited experience of palliative care, should ideally be included in the palliative care team as they are likely to have a thorough understanding of the child and family, and be better placed to provide day-to-day services to the child and family. Further,

physicians specialising in adult palliative care may be involved in providing advice on case management, along with social workers, teachers, psychologists, paediatric and paediatric palliative care nurses.

Children suffering life-limiting conditions are likely to move between hospital and community settings and, as Hynson and Sawyer (2001) noted, providing palliative care requires considerable coordination and overcoming barriers between the hospital and the community. They also state that the effective collaboration between providers, particularly for families living in rural or remote areas where immediate access to, and management by, specialist staff is impractical, is essential if these families are to receive comprehensive and appropriate care. The role of local general practitioners and nursing staff who, as noted previously, may only experience one or two cases in their careers, becomes crucial and the capacity of services to support their role essential.

Paediatric palliative care services

The development of the palliative care specialty is relatively recent. Hynson and Sawyer (2001) stated that the needs of dying children have not been addressed to the same extent as the needs of dying older patients. They speculate that this difference may be because of the comparative rareness of children needing palliative care and the difficulties in differentiating between active treatment and palliative care in children and adolescents.

While there are commonalities between palliative care for children and adults, a crucial aspect of paediatric palliative care is the recognition that there are important differences between children and adults, which must be recognised and addressed in service provision. Among these differences are the variations in patient diagnoses; the developmental, psychological and social needs of children; the unique place of children as dependent members of families; the particular ethical issues involved where minors are concerned and the physiological factors that relate specifically to children and their illnesses.

Darbyshire, Haller and Flemings (1997) also referred to the greater emotional burden facing carers and the increased clinical complexity associated with paediatric palliative care. The American Academy of Pediatrics (AAP 2000) affirmed that the illnesses of children and adults undergoing palliative care are very different and that therefore the models of care require further development.

Trends in developing and providing models for paediatric palliative care

Worldwide, an estimated seven million children and their families could benefit from hospice care and many more from palliative care (Rushton and Catlin 2002). As would be expected, the quality and nature of services provided varies greatly across the world and even within countries. A general trend is that children with life-threatening chronic conditions are living longer (AAP 2000). This results in longer periods of palliative treatment, more complex care requirements and greater uncertainty in estimating prognoses and length of life.

In the UK (NCHSPCS et al 2001), there are a number of models of paediatric palliative care, most drawn from the model set up to care for children dying from cancer. The paediatric oncology model is based on paediatric oncology nurses who work out of tertiary centres or district hospitals. The nurses are supported by social work teams and paediatric oncologists, paediatricians, general practitioners and sometimes adult palliative care specialists.

The most recently developed model of care for children with life-threatening illnesses in the UK is the independent and charity-sponsored Children's Hospice (Martinson 1995; Eve 1996; Eve, Smith and

Tebbit 1997; Gold 1997; Davies 1998; Overton 2001). In 2002, this program ran approximately 23 children's inpatient hospices and a network of specially trained paediatric nurses and other community-based paediatric providers. In addition, it had a centralised education and backup system for children's uncontrolled symptoms that was accessible 24 hours a day. The admission criterion for the UK programs was that the child is not expected to survive to become an adult.

These children's hospices support children with life-limiting conditions and their families at the point of diagnosis or when treatment is abandoned, and aims to help families with this burden of care, enabling them to enjoy time with their dying children, the siblings or on their own. These facilities are characterised by flexible, family-centred care, support and friendship throughout the course of a child's illness, which continues after the child dies. The care is individually tailored to the needs of families.

Hospice services are provided by multiskilled teams that allow the wide-ranging needs of the children and their families (whether physical, emotional, play and learning, social or spiritual) to be met. The care teams at all children's hospices are led by a qualified children's nurse. The key features of this model of care include:

- specialist respite, emergency, palliative and terminal care (that can be offered within the hospice or family home);
- bereavement counselling and support (offered as individual home support, in groups and with siblings);
- information, advice and practical assistance;
- 24-hour telephone support;
- a volunteer support service (that ensures families are supported);
- collaborative working arrangements with other agencies and individuals to ensure a continuum of care and support is available to the children and families, and that the families have choices about care and the place of death; and
- provision of information, expert help and guidance for others involved with the child and family.

A further UK development has been the establishment and funding (in memory of Diana, Princess of Wales) of a network of community children's nurses who have a particular responsibility for children with a life-threatening illness. It is envisioned that these 'Diana teams' (see Davies 1999) will work with many seriously ill and dying children and their families. It is likely, though unevaluated as yet, that this collaboration with existing services and specific support for families should improve families' real choices regarding their child's place of death. In 1993, Pinkerton stated that the 'vast majority' of children in the UK receiving palliative care die at home but, given the rise in the children's hospice movement in the UK, it may well be the case that now more children die in a hospice setting.

Commentators in the USA seem less optimistic regarding their situation. Marcia Levetown, founder of the Children's International Project on Palliative/Hospice Services (ChIPPS) in 1996 noted that (Larkin 2000)

The UK, Canada, and Australia are 'way ahead' of the USA when it comes to the provision of palliative and hospice care for children ... Outside the USA, it is acknowledged that children die. Here, we're not used to that fact and don't provide for it.

Other reviews of the North American situation (Children's Hospice International 1986) have concluded that, 'In the United States alone, one million children are very seriously ill.' Levetown (1996) noted that approximately 400,000 children are living in the USA with chronic, life-threatening conditions. Approximately 55,000 children die annually, with only 5,000–7,000 receiving hospice services at the time of death and very few children receiving longer term palliative care services (Levetown 1996). In the USA, the largest percentage of children die in institutions, primarily hospitals. Most often, the place where death occurs is the critical care setting (Rushton and Catlin 2002).

In Australia, geography has certainly influenced the development of paediatric palliative care services in that the numbers of children requiring paediatric palliative care in an area have not seemed numerically significant enough to constitute a demand for specific services. A similar influencing factor has been the difficulty in establishing a 'critical mass' of health care professionals experienced and qualified in paediatric palliative care.

A further factor that has shaped Australian development in this area has been that the Australian paediatric palliative care movement has emerged predominantly from paediatric oncology services. This has now broadened, however, to recognise that the picture of paediatric palliative care in Australian children is one in which more than half of children referred have terminal diagnoses other than those resulting from childhood cancer. Mallison and Jones (2000) highlighted the gradual increase, from 1991 to 1997, in the number of children dying at home or in hospices instead of in the acute hospital setting in Australia.

Key features of paediatric palliative care models

Fragar (1996, p 12), in a review of international models of paediatric palliative care and gaps in services, concluded that

Currently the provision of palliative care is patchy and inconsistent. What is needed is a systematic and comprehensive approach to all children with significant life-threatening diseases to ensure that their special needs are met.

Hynson and Sawyer (2001) state that there is little hard evidence to support one model of paediatric palliative care over another and that more evidence-based research is necessary. Much of the literature referred not to models of care but to elements of care that were found to be effective. Hynson and Sawyer (2001) refer to the recommended components of care listed by the Royal College of Paediatrics and Child Health and the Association for Children with Life-threatening or Terminal Conditions. These components include:

detailed care planning, the use of a key worker, involvement of a paediatrician, 24-hour support and the utilisation of clinicians, nurses and therapists skilled in children's palliative care.

McGrath (1990), among others, referred to the different pain relief needs of children and adults and discussed the New Zealand Ministry of Health (2001) strategy that advocates that children who are dying have available to them the expertise of a paediatrician and a paediatric nurse with palliative care experience, as well as a care coordinator. As only a relatively small number of children require palliative care services, New Zealand has implemented a national palliative care group to provide advice and guidance to local service providers.

The issue of when to commence palliative services is seen as problematic. As stated earlier in this document, it is often difficult to distinguish between the end of curative treatment services and the start of palliative care services. The American Academy of Pediatrics (2000) stated that palliative services may be beneficial to children even while curative treatment is still occurring. The academy suggests that palliative services be considered for all children living with a life-threatening condition. The ChIPPS (2001) stated that a short-term prognosis of death is not a suitable determinant for the referral of children to palliative care, as the death of a child is difficult to predict. Rather, the trigger should be that a child is not predicted to survive to adulthood.

The importance of a continuum in the services provided is discussed in the literature. As noted by Hynson and Sawyer (2001), the transition from curative to palliative care is often less clear in the paediatric context. In examining existing services, gaining an understanding of those factors or criteria that initiate services to children and their families will be important. On the other hand, Darbyshire, Haller and Flemings (1997) noted the abandonment felt by some families as involvement with, and support from, the palliative care providers ceased once the child has died. Hynson and Sawyer (2001) recommended the continuing involvement of the paediatrician with the palliative care team, as well as that of the general practitioner. Darbyshire, Haller and Flemings (1997) recommended the appointment of paediatric palliative care coordinators to reduce the fragmentation of care.

The involvement of the affected families and children in the development of care plans is seen as important by the majority of researchers. The American Academy of Pediatrics (2000) recommends that a developmentally appropriate explanation of the condition and the potential benefits of treatment options be given to children and their preferences solicited.

Home-based care is considered to be a desirable service. Mallison and Jones (2000) stated that the choice of hospital or home as the treatment location must be a decision carefully made by families and children and it must be supported by the treating clinicians. Hynson and Sawyer (2001) stated that home care is a preferred outcome for families, and many of the conditions seen in paediatric palliative care can be managed appropriately at home with the necessary level of clinical support.

Communication between all parties is considered to be vital to successful palliative care. As already indicated, a number of health professionals rarely experience the death of a child for whom they are caring. Mallison and Jones (2000) highlighted the importance of the paediatricians' communication to all members of their care team to overcome some clinicians' fear and inexperience regarding caring for dying children. Pinkerton (1993) stated that communication with the family about what they can expect from any treatment and the potential outcomes should begin even before a diagnosis is made, especially when the family will be attending specialist units for diagnosis. Pinkerton suggested the involvement of other disciplines, such as paediatric nurses, social workers, psychologists and so on in the communication process, whenever appropriate.

In the work undertaken by Ashby and colleagues (1991), families cited good information as one of their highest priority needs. Darbyshire, Haller and Flemings (1997) reported that clear and unambiguous information for parents on all aspects of death and dying is vital. Contro and colleagues (2002) found that families appreciated important news being given by a familiar caregiver. Hilden and colleagues (2001) reported that communicating with families about pain management and the shift to palliative care was seen as a problem by paediatric oncologists.

Emotional and social support was seen as a very important part of palliative care. Ashby and colleagues (1991) cited families needing access to the palliative care team for some time after the death of the child. Hynson and Sawyer (2001) stated that including the emotional needs of siblings into the palliative care

plan is important for the future health of the family. Contro and colleagues (2002) also reported that siblings need an appropriate infrastructure in the hospital environment, such as playrooms, support groups and respectful treatment by staff.

Support for staff caring for dying children is also important. McHaffie and Fowley (1998) reported that treating physicians saw the ability to consult with colleagues and to gain second opinions as important, especially when making decisions regarding the cessation of intensive treatment.

The importance of educating staff about caring for dying children and their families was stated by many researchers. Ashby and colleagues (1991) discussed the need for staff to understand the emotional reactions of children receiving palliative care, and their families. The literature, in particular Darbyshire, Haller and Flemings 1997 and Contro and colleagues 2002, stated that often home care staff were inexperienced and untrained in the care of dying children. Hilden and colleagues (2001) found that paediatric oncologists reported a lack of education in paediatric palliative care and relied on 'trial and error' when making treatment decisions.

A further significant trend that has affected paediatric palliative care as markedly as it has in other areas of health care has been the focus on the 'consumer', on those children and families who are on the receiving end of services and health professionals' attentions. This heightened sensitivity and responsiveness to the needs and wishes of children and families has been evident in the many attempts made to ascertain more clearly what families need and want from a paediatric palliative care service (Collins, Stevens and Cousens 1998).

Guidelines

With the growth in interest in paediatric palliative care has come a range of guidelines and suggestions for service planning, delivery, development and evaluation. Guidelines for paediatric palliative care are available from a range of organisations, individual institutions and from clinicians and researchers. Significantly, perhaps the bulk of such clinician/researcher recommendations are published by doctors.

While guidelines may differ in degree and detail, most include suggestions and principles that would be widely, if not universally, accepted (Liben and Goldman 1998; Collins, Stevens and Cousens 1998; Worden and Monahan 1995). Among these principles would be:

- enabling families to make the choices and decisions regarding paediatric palliative care that are best for them and their children;
- providing parents and carers with the knowledge and understanding that they require in order to make the best informed decisions;
- being flexible and accommodating, letting parents and carers know that they can change their minds and that this is okay;
- ensuring that services are as open, equitable and easily accessible as possible, day and night;
- ensuring that coordination between the paediatric palliative care service and associated services and agencies is real and obvious to families;
- recognising bereavement support for parents and siblings as a vital component of a paediatric palliative care service and as different from the adult model because of its increased duration and intensity; and
- ensuring that those involved in providing paediatric palliative care have the relevant expertise in both caring for children and families and palliative care itself.

While many guidelines address the broad principles of service provision and policy, others are more akin to clinical standards and will focus on specific aspects of the care and management of the child, for example, the symptoms and suffering (see Goldman 1998, McGrath 1996).

Evaluation of paediatric palliative care services and indicators used

Palliative Care Australia (PCA 1998b) held a performance indicators planning workshop in February 1998. This workshop resulted in the development of a number of indicators for palliative care to be used at the state or national level. The report acknowledged that the first eight indicators were useful as a design framework for individual paediatric palliative care programs. The indicators identified by the workshop are:

- the utilisation of interdisciplinary assessment and planning of care,
- the utilisation of multidisciplinary service contacts with families,
- that the place of death while receiving palliative care is in accordance with family needs,
- the provision of a comprehensive patient-centred assessment completed on admission,
- the provision of pain assessment,
- the provision of pain management,
- the provision of pain control and the monitoring and reporting of outcomes,
- the availability of an interdisciplinary team,
- the number of services using a shared record,
- the proportion of patients for whom a shared record exists,
- the ratio of volunteer coordinator hours to volunteer hours provided to the service,
- the proportion of volunteer services with a designated budget,
- the total annual hours of professional education provided,
- the total annual hours of community education provided,
- the proportion of palliative care services accredited with the Australian Council on Health Care Standards using the 1996 palliative care guidelines,
- the total annual hours of community education provided,
- that palliative care services have at least one appropriate benchmarking partner,
- the level of satisfaction with the care provided by the palliative care service,
- that palliative care services apply a bereavement risk assessment to all primary carers,
- that bereavement services are provided with a funded coordinator, and
- the proportion of palliative care services that provide 24-hour access.

The report found that there was not yet a valid measure of satisfaction with palliative care services and recommended that work be undertaken in designing such a measure.

It is perhaps a measure of the developing nature of paediatric palliative care services that few if any large-scale systematic reviews have been undertaken of paediatric palliative care programs and approaches. A compounding difficulty here is also the elusive nature of many of the outcomes or end points of

paediatric palliative care. For example, how would we quantitatively evaluate a central tenet of paediatric palliative care such as a 'good death' or a family's sense of peace, or their knowledge that they handled this extremely difficult situation as best they could. Similarly, how could the language of costs, benefits and 'value for money' be fittingly applied to the death of one's child?

In a study of neonates and infants in the USA, Pierucci, Kirby and Leuthner (2001) conducted a retrospective chart review to determine the effects of paediatric palliative care consultations on both the infants and their families. The researchers concluded that (p 653), in this most highly technical and medical environment,

Infants of families that received consultations had fewer days in intensive care units, blood draws, central lines, feeding tubes, vasopressor and paralytic drug use, mechanical ventilation, cardiopulmonary resuscitation, and x-rays, and the families had more frequent referrals for chaplains and social services than families that did not have palliative care consultations ... This suggests that palliative care consultation may enhance end-of-life care for newborns.

In response to the above difficulties, researchers have undertaken more qualitative approaches to evaluating paediatric palliative care, focusing on the responses of parents and families who have directly experienced this situation (Vickers and Carlisle 2000; Dangel et al 2000; Pierucci, Kirby and Leuthner 2001; Collins, Stevens and Cousens 1998; Darbyshire, Haller and Flemings 1997).

Where is the families' perspective?

A search and critique of existing literature revealed that there were significant gaps in our research-based understandings of how families experienced the period of their child's palliative care. While much research exists on the broad theme of 'parents and the death of a child', few studies seem to have been undertaken that directly sought the perspectives of the wider family (parents, siblings, grandparents and so on) on the child's palliative care. Early Australian reports highlighted the considerable palliative care and bereavement needs of families whose child is dying, yet who may not be receiving the support and care services which can best help them through this immensely painful and traumatic time.

In the South Australian context, it was proposed that a study of parental needs and patient needs should be done as a matter of urgency. This research priority was later reinforced by the IWGDDB, which concluded its position statement on palliative care for children by noting the need for research examining 'how the ill child and individual family members experience the progression of the illness, the threat, and the reality of death' (IWGDDB 1993). More recent research into paediatric palliative care continues to recognise the paucity of studies that have sought to directly explore parents' experiences of providing palliative care for their child (Davies et al 1998). In a recent review of palliative care research in general, the researchers concluded that, 'Little research on families/carers of palliative care patients was evident (Wilkes, Tracy and White 2000).

There is, of course, a wide range of tangential literature related to paediatric palliative care. Studies of adult palliative care, of the care of dying children, of parental grief (Jacob and Scandrett-Hibdon 1994) and of that somewhat inadequate concept, 'coping', may all contribute to a background understanding of families' experiences. There is, however, wide agreement about the crucial importance of parents' and relatives' relationships with health care staff. Andershed and Ternstedt (2001, p 554) summarised this when they concluded that

the manner in which staff act towards the patient and relatives influences relatives' possibilities for involvement, patients' possibilities for an appropriate death and the possibility the staff have to give good care.

Summary of literature review findings

The review of the literature has revealed the following:

- 1 The majority of reports about models of paediatric palliative care are of a strategic nature. They refer to intentions for developing models of paediatric palliative care, rather than reporting on models. Most discussions regarding existing services refer to desirable components of services.
- 2 The key elements of good practice models of care in existence and recommended elements of a good practice model include: providing detailed care planning, using a key worker, involving a paediatrician, providing 24-hour support and using clinicians, nurses and therapists skilled in paediatric palliative care.
- 3 In recent times paediatric palliative care has been seen as a separate discipline to adult palliative care.
- 4 The trends in palliative care, including paediatric palliative care, are toward a larger proportion of home-based care.
- 5 The relative rarity of childhood death means that many clinicians do not have a great deal of experience in treating dying children and caring for their families.
- 6 The paediatric palliative care team should be multidisciplinary and should include general practitioners, paediatric specialists, paediatric palliative nurses and clinicians, where available, and social workers. Other allied health practitioners may have to be involved. Where there are no paediatric palliative specialists, adult palliative clinicians may form part of the team.
- 7 Paediatric palliative care requires considerable coordination between hospital and community settings. Case managers should be assigned to coordinate this care.
- 8 While the basics of palliative care are the same for adults and children, there are a number of factors, including developmental differences and the greater prevalence of rare conditions, that mean that models of adult palliative care cannot be directly applied to models of paediatric care.
- 9 Children with life-threatening conditions are living longer and therefore require longer periods of palliative services.
- 10 The pain relief needs of children are different to those of adults because of physiological differences and because children absorb, distribute, metabolise and excrete drugs differently from adults.
- 11 Guidelines on when to commence palliative care should be carefully considered as many palliative services may be appropriately commenced during courses of active treatment. In addition, definitions that refer to the time remaining before death is expected are more difficult to apply to children, as the time of death is more difficult to predict.
- 12 Children should be involved in care decisions as appropriate for their conditions and developmental stages. Families must be involved in care planning and decisions.
- 13 Good, complete, clear and unambiguous communication with the families, children and within the care team is paramount.
- 14 Emotional and social support for families, children, siblings and care providers is important.
- 15 Effective education for staff in the care of dying children and their families is a vital component of good paediatric palliative care.
- 16 Guidelines on pain relief are available from the World Health Organization.

- 17 Guidelines that support the appropriate continuation of palliative services once intensive treatment has ceased, and differentiate that care from euthanasia, are important.
- 18 Palliative Care Australia has developed a series of performance indicators for palliative care, many of which are applicable to individual programs.
- 19 Measures of patient and carer satisfaction with paediatric palliative care are still being designed.

The findings of our literature review were used to develop a comprehensive understanding of the types of models of paediatric palliative care that are being utilised globally, and to formulate a number of service delivery strategies that are presented in chapter 8 of this report.

Chapter 4

Paediatric palliative care survey analysis



This chapter presents the results of the analysis of the surveys returned by palliative care agencies. Its focus is on providing a comprehensive profile of services, including organisational characteristics, approaches to services, client groups targeted, comparisons of community and hospital-based care, and so on.

Structure of survey form and process

Before we present the data, we will outline the key elements of the survey form and process. As previously stated, the survey was conducted to obtain:

- a profile of existing paediatric palliative care services across Australia, in order to describe their operational aspects and the types of services provided;
- a profile of paediatric palliative care clients who received services during 2001–2002;
- a description of the costs of service delivery with respect to client conditions and the types of services provided; and
- an understanding of the degree to which client needs are being met and the reasons these needs are not being met.

Compilation of palliative service agencies to be surveyed

As previously stated, the target population for this survey was all palliative care agencies. Based on the advice of the project steering committee, HMA approached Palliative Care Australia for a list of agencies that were registered members. As part of developing the survey database, we completed a review of this list, which showed that many of the specialist paediatric hospitals were not listed as members. These hospitals were subsequently added to the list of agencies to be surveyed. It is important to note that, while every attempt was made to identify all palliative care service providers, it is possible that a small number have been excluded from the survey process.

From the outset our preliminary research indicated that, for many service providers, the data required for this survey would not be readily available, and would necessitate a manual extraction and compilation process. In addition, we were also aware that, to a large extent, the costs associated with providing paediatric palliative care were indistinguishable from other costs in existing financial management information systems. In these instances, respondents were requested to provide an estimate of these costs based on local knowledge.

A copy of the survey form is presented in appendix A of this report.

Survey summary statistics

As previously indicated, the survey included all palliative care service providers with both adult and paediatric clients.

TABLE 1: SUMMARY OF PALLIATIVE CARE SURVEY STATISTICS BY STATE AND TERRITORY

State or territory	Survey forms sent	Survey forms received	Nil respondents	Compliance rate
ACT	4	3	1	75.0%
NSW	103	71	32	68.9%
NT	9	7	2	77.8%
QLD	67	45	22	67.2%
SA	31	22	9	71.0%
TAS	15	11	4	73.3%
VIC	92	64	28	69.6%
WA	43	30	13	69.8%
Total	364	253	111	69.5%

As indicated in table 1 above, a total of 364 palliative care agencies were surveyed across Australia. Of the agencies surveyed, 253 responded to this survey, representing a 70% compliance rate. This relatively high response rate is indicative of the high level of effort expended and support provided by the participants in the survey. There were 111 agencies that did not provide data.

Table 2 summarises the numbers of responding agencies that provided palliative care services to children with life-limiting conditions during 2001–2002 and shows that 125 agencies (49.4% of respondents) had the capacity to provide these services, but only 74 actually did have paediatric clients in that year. Of the responding agencies that indicated they did provide paediatric palliative care (PPC) to clients, 22 (17.6%) were unable to provide details of the costs of services provided.

Respondents were asked to complete all the survey questions only if they were paediatric palliative care providers, so the data represented below are drawn from the answers of those 125 agencies that said they were able to provide paediatric palliative care, including the 74 that actually provided that kind of care to clients during 2001–2002.

TABLE 2: RESPONDING AGENCIES PROVIDING PAEDIATRIC PALLIATIVE CARE 2001–2002 AND THOSE UNABLE TO PROVIDE COSTS OF SERVICES, BY STATE AND TERRITORY

State or territory	Total no of agencies able to provide PPC services	Total no of agencies providing PPC services in 2001–2002	No of agencies providing PPC nil \$	% agencies nil \$
ACT	1	1	0	0.0%
NSW	46	27	14	11.2%
NT	3	3	1	0.8%
QLD	18	12	2	1.6%
SA	10	6	0	0.0%
TAS	6	1	0	0.0%
VIC	27	17	2	1.6%
WA	14	7	3	2.4%
Total	125	74	22	17.6%

Analysis of survey data

Given that the survey did not achieve full enumeration of palliative care service providers (the number of providers is actually not known as there is no population database for palliative care services), and that a significant proportion did not respond to the survey or missed data elements, it was considered inappropriate to use absolute numbers extensively in the survey analysis. We considered it better to report that zz% of palliative care service providers offered paediatric palliative care services. However, some absolute numbers have been used. Sometimes the rounding of figures means that percentages will not add up to 100.

Profile of service providers

This section provides a profile of paediatric service providers with respect to the availability of their services by outlining the number of services, the location and business operation hours and the types of services that were offered.

Paediatric palliative care service providers

One of the objectives of this research project was to identify the number of paediatric palliative care service providers across Australia. Question (Q) 1 of the survey form asked respondents to indicate whether the organisation provided paediatric palliative care services (PCS).

FIGURE 1: PROPORTIONS OF RESPONDING AGENCIES PROVIDING ADULT AND PAEDIATRIC PALLIATIVE CARE SERVICES IN 2001–2002

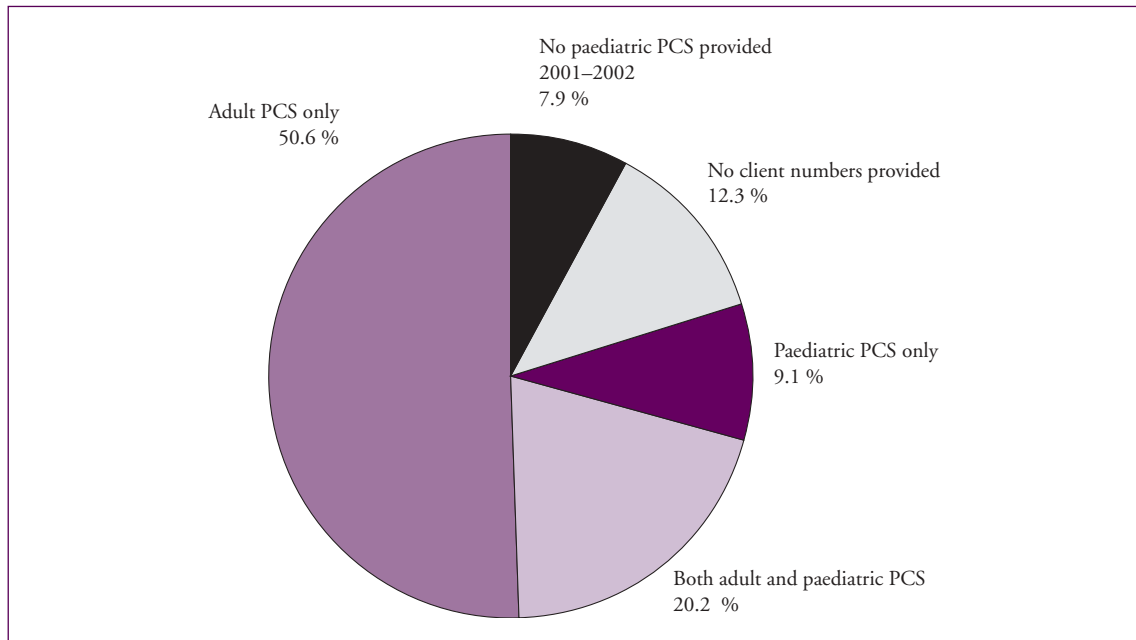


Figure 1 shows that, for the 2001–2002 financial year, 50.6% of the 253 responding agencies indicated that they were providers of adult palliative care services, while 9.1% of agencies provided paediatric palliative care to registered clients and 20.2% provided both adult and paediatric palliative care.

Table 3 shows the proportion of responding adult (128 agencies in total) and paediatric palliative care providers (125 agencies) in each state. This table shows that Victoria had the largest proportion of adult palliative care agencies (28.9%). New South Wales and Victoria had the highest proportion of paediatric palliative care agencies (36.8% and 21.6% respectively).

TABLE 3: PROPORTION OF RESPONDING ADULT AND PAEDIATRIC PALLIATIVE CARE SERVICE PROVIDERS IN 2001–2002 BY STATE AND TERRITORY

State or territory	% Adult PCS	% Paediatric PCS
ACT	1.6%	0.8%
NSW	19.5%	36.8%
NT	3.1%	2.4%
QLD	21.1%	14.4%
SA	9.4%	8.0%
TAS	3.9%	4.8%
VIC	28.9%	21.6%
WA	12.5%	11.2%
Total	100.0%	100.0%

Accessibility of paediatric palliative care services

The accessibility of paediatric palliative care services has been identified by a number of research studies as problematic. Question 3 in the survey sought to identify the catchment area of these services. Figure 2 shows the proportion of responding agencies that offered paediatric palliative care services at the local, regional, statewide and government services levels across Australia.

FIGURE 2: PROPORTION OF RESPONDING AGENCIES OFFERING LOCAL, REGIONAL, STATEWIDE AND OTHER PAEDIATRIC SERVICES IN 2001–2002

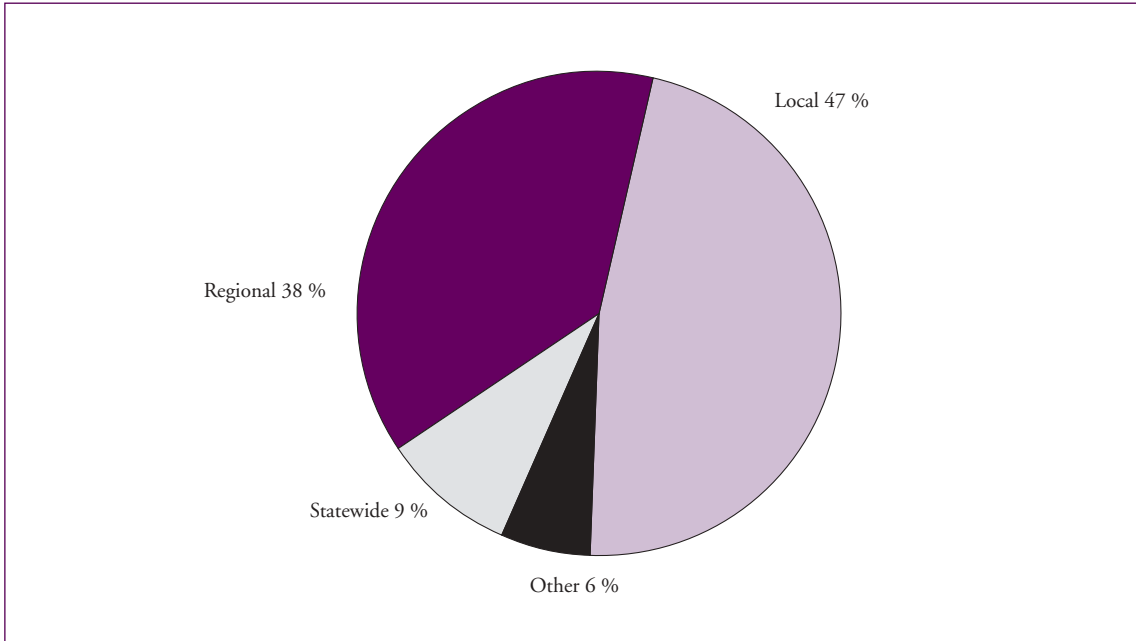


Figure 2 shows that 47% of responding agencies that offered paediatric palliative care services focused on doing so within their local area, 38% of agencies provided services on a regional basis, and 9% of agencies had statewide responsibilities for paediatric palliative care service provision. Six per cent of agencies provided a number of other responses, including that they provided national, interstate, network and local government services.

A state-based analysis of these results is presented in table 4 below. This table shows the proportion of responding paediatric palliative care services (125 agencies) that offered local, regional, statewide and local government services in each state. New South Wales had the largest proportion of local paediatric palliative care services (24.8%) and the highest proportion of total paediatric palliative care services (36.8%). Victoria reported the highest proportion of regional services (12%), which is an outcome of the state’s paediatric palliative care strategy and the progressive implementation of the Victorian Paediatric Palliative Care Program. Considerably fewer services were available in the remaining states and territories, notably the ACT (0.8%) (for the most part, children from the ACT go to New South Wales to receive services), the Northern Territory (2.4%) and Tasmania (4.8%).

TABLE 4: STATE AND TERRITORY PROFILE OF RESPONDING AGENCIES OFFERING LOCAL, REGIONAL, STATEWIDE AND LOCAL GOVERNMENT SERVICES IN 2001–2002

State or territory	% Local services	% Regional services	% Statewide services	% Other (local govt and other)	% Total PPC agencies
ACT	0.0%	0.0%	0.8%	0.0%	0.8%
NSW	24.8%	7.2%	1.6%	3.2%	36.8%
NT	0.8%	1.6%	0.0%	0.0%	2.4%
QLD	6.4%	7.2%	0.0%	0.8%	14.4%
SA	1.6%	4.8%	0.8%	0.8%	8.0%
TAS	0.0%	3.2%	1.6%	0.0%	4.8%
VIC	5.6%	12.0%	2.4%	1.6%	21.6%
WA	7.2%	2.4%	1.6%	0.0%	11.2%
Total	46.4%	38.4%	8.8%	6.4%	100.0%

Hours of service coverage

The need for greater accessibility of paediatric palliative care services has been highlighted by various research studies that have been undertaken in Australia and overseas. The intent of Q4 in the survey was to find out the number of funded service operation hours. Figure 3 shows the primary response to this question. These data show that 60% of responding agencies across Australia provided 24-hour telephone access for families requiring paediatric palliative care, and approximately 10% of agencies provided a seven-days-a-week service. Given the findings of our literature review, the relatively low numbers of agencies providing services on a seven-days-a-week basis suggest that more innovative models of care should be developed to provide greater accessibility of services to families requiring paediatric palliative care support after business hours, when support is most often required.

FIGURE 3: PROPORTION OF TYPES OF SERVICES PROVIDED BY RESPONDING AGENCIES IN 2001–2002

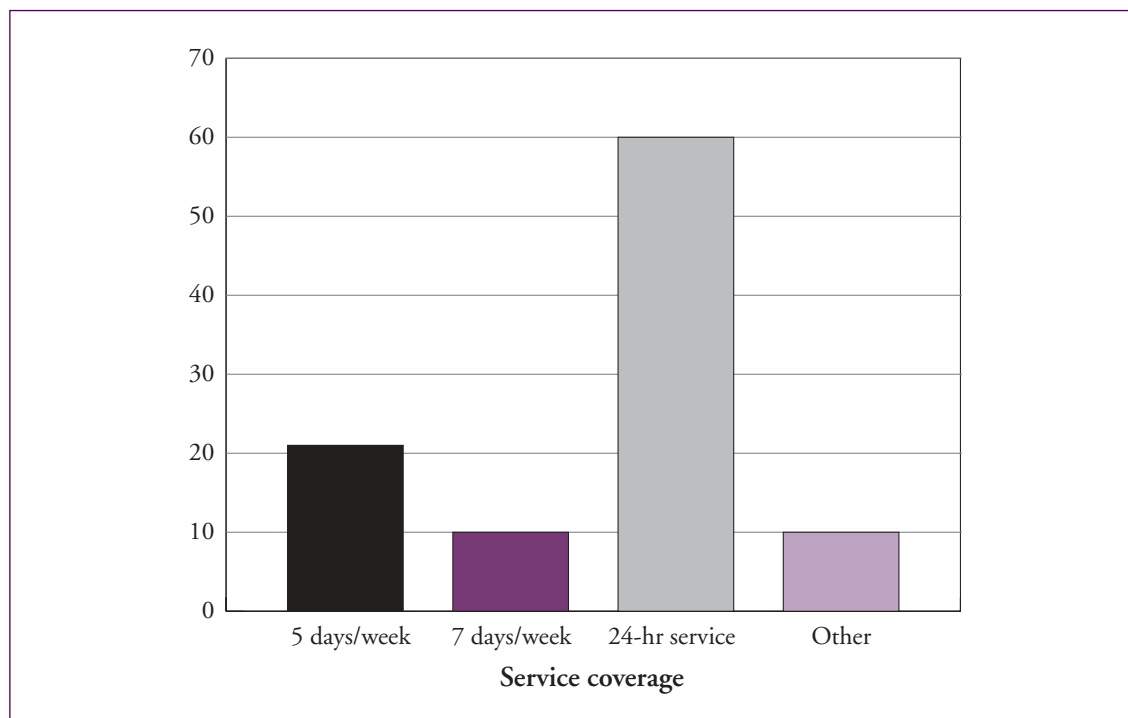


Table 5 below shows the proportion of the different kinds of service coverage provided by the 125 responding agencies as measured by the operational business hours spent providing those services.

TABLE 5: PROPORTION OF TYPES OF SERVICES PROVIDED BY RESPONDING AGENCIES IN 2001–2002, BY STATE AND TERRITORY

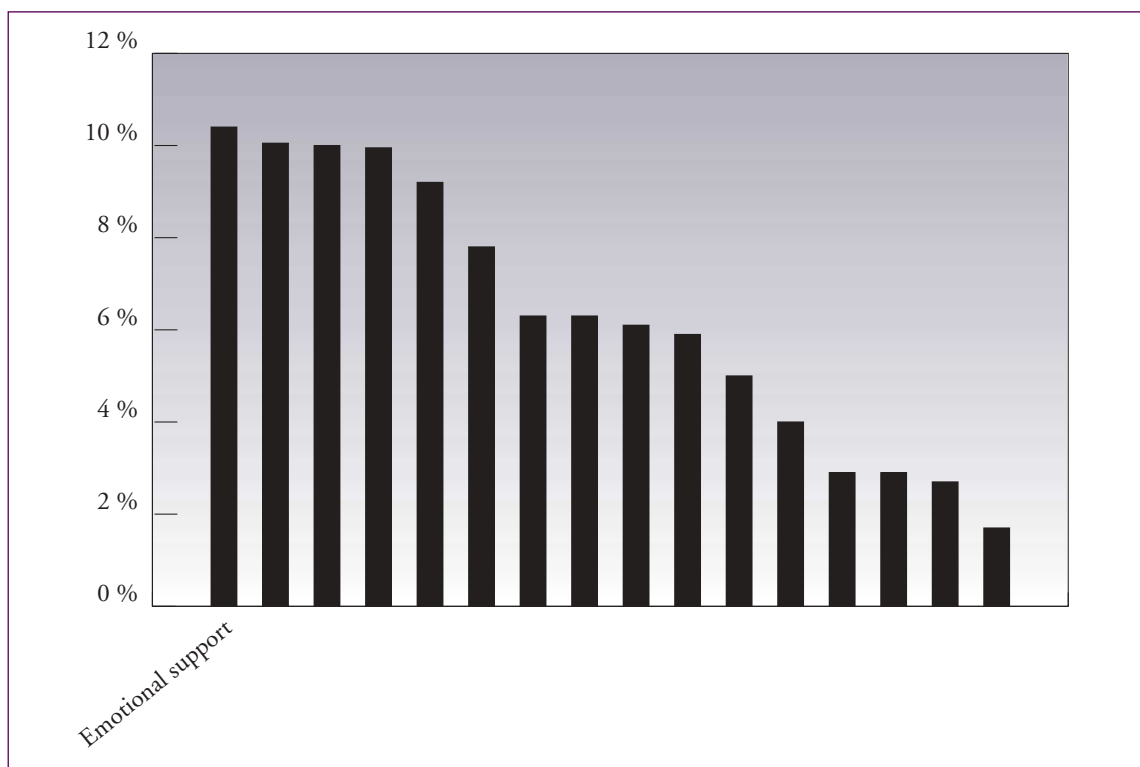
State or territory	% Agency business hours				
	5 days a week	6 days a week	7 days a week	24-hour service	Additional services outside normal hours
ACT	0.0%	0.0%	0.0%	0.8%	0.0%
NSW	6.4%	0.0%	6.4%	17.6%	6.4%
NT	0.0%	0.0%	0.0%	1.6%	0.8%
QLD	2.4%	0.0%	0.8%	11.2%	0.0%
SA	1.6%	0.0%	0.0%	5.6%	0.8%
TAS	2.4%	0.0%	0.0%	2.4%	0.0%
VIC	5.6%	0.0%	2.4%	12.0%	1.6%
WA	2.4%	0.0%	0.0%	8.8%	0.0%
Total	20.8%	0.0%	9.6%	60.0%	9.6%

Table 5 indicates that a 24-hour service was available in each state, however, there was greater access to this type of service in New South Wales, Victoria and Queensland, where networks of telephone support services are provided. New South Wales, Victoria and Queensland were the only states that provided seven-days-a-week access for paediatric palliative care services and that was restricted to 10% of respondents. The distribution of five-days-a-week paediatric palliative care services was relatively similar across all states, with the notable exceptions of the ACT and the Northern Territory, where no services were reported.

Types of paediatric palliative care services

Figure 4 shows the profile of the types of paediatric palliative care services offered by responding agencies and the proportion of these services offered across Australia.

FIGURE 4: TYPES OF PPC SERVICES OFFERED BY RESPONDING AGENCIES IN 2001–2002



These data suggest that, of the total services offered, approximately 40% were dedicated to providing emotional support, community-based care, symptom control and information. The survey data also demonstrate the limited availability of bereavement support (9%), respite care (6%) and sibling support (4%). Adjuvant therapy (for example, chemotherapy) was only available at the major paediatric tertiary referral hospitals in each state.

Profile of staff employed in paediatric palliative care services

In Q15 of the survey, agencies were requested to record the number of staff (reported as full-time equivalents or FTEs) they employed as at 30 June 2002. Table 6 shows the staffing mix reported by the

125 responding paediatric palliative care agencies, expressed as a percentage of their total staff numbers. It is important to note that the FTEs in this analysis represent those staff employed by the agency, and do not include staff from other units (for example, within hospitals) that may be involved in providing paediatric palliative care. South Australia, however, made an attempt to estimate other staff involved in providing care, and these have been reported under the 'other staff' category.

TABLE 6: STAFFING MIX OF RESPONDING AGENCIES AT 30 JUNE 2002, BY STATE AND TERRITORY

Staff category	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	% FTE of total
Paediatrician oncologists	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.7%	0.7%
Palliative physicians	0.0%	1.9%	0.9%	0.1%	0.6%	0.7%	0.8%	0.2%	5.3%
Pain management specialists	0.1%	0.1%	0.0%	0.0%	0.0%	0.0%	0.0%	0.3%	0.5%
Paediatricians	0.0%	0.5%	0.0%	0.2%	0.0%	0.0%	0.1%	0.0%	0.7%
Oncologists	0.0%	0.5%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.5%
General practitioners	0.0%	0.9%	0.0%	0.0%	0.0%	0.0%	0.0%	0.6%	1.6%
Paediatric palliative nurses	0.0%	0.7%	0.0%	0.2%	0.2%	0.0%	0.4%	0.1%	1.6%
Registered nurses	0.9%	19.7%	0.5%	5.0%	3.9%	2.3%	8.0%	3.9%	44.1%
Social workers	0.0%	1.3%	0.1%	0.3%	1.6%	0.5%	2.5%	0.3%	6.6%
Chaplains	0.0%	0.5%	0.0%	0.0%	0.2%	0.0%	0.0%	0.5%	1.2%
Pastoral care workers	0.0%	0.1%	0.1%	0.2%	0.1%	0.0%	0.3%	0.0%	0.7%
Physiotherapists	0.1%	0.5%	0.0%	0.0%	1.2%	0.0%	0.0%	0.2%	2.0%
Occupational therapists	0.1%	0.6%	0.1%	0.0%	0.9%	0.0%	0.0%	0.3%	1.9%
Psychologists	0.0%	0.3%	0.0%	0.1%	0.1%	0.0%	0.5%	0.2%	1.1%
Mental health workers	0.0%	0.2%	0.0%	0.0%	0.4%	0.0%	0.0%	0.9%	1.4%
Other allied health staff	0.0%	0.6%	0.0%	0.1%	0.0%	0.0%	1.1%	1.4%	3.2%
Administrative staff	0.0%	2.1%	0.0%	0.7%	2.8%	0.4%	2.8%	0.1%	8.9%
Other staff	0.0%	5.1%	0.0%	1.5%	6.7%	1.1%	3.4%	0.1%	17.9%
Total FTEs	1.2%	35.5%	1.6%	8.4%	18.6%	5.0%	19.8%	9.9%	100.0%

Note: Percentages in this table have been rounded up to one significant figure.

Table 6 shows that, as at 30 June 2002:

- registered nurses represented 44% of the total staff employed to provide paediatric palliative care;
- only 1.6% of nurses had a paediatric palliative care qualification; and
- medical practitioners represented 9.3% of the total workforce, the highest proportion were classified as palliative care physicians (5.3%) and approximately 1.6% were general practitioners.

Based on our literature review findings, these results indicate that additional resources are required to employ qualified paediatric palliative care medical and nursing staff, mental health workers, psychologists and pastoral care staff to ensure that a comprehensive paediatric palliative care service is provided.

Proportion of voluntary services used

Table 7 shows the number of responding agencies that provided volunteer support services by state and territory, and the proportion of total hours of service provided by voluntary services.

**TABLE 7: PROPORTION OF HOURS SPENT IN VOLUNTARY SERVICE
IN RESPONDING AGENCIES IN 2001–2002, BY STATE AND TERRITORY**

State or territory	No of agencies	% of total hours
ACT	0	0.0%
NSW	7	11.8%
NT	1	0.0%
QLD	4	3.2%
SA	2	0.2%
TAS	1	0.1%
VIC	6	83.9%
WA	3	0.8%
Total	24	100.0%

Table 7 shows a total of 24 responding agencies provided volunteer support services across Australia to paediatric palliative care clients. There was considerable variability in access to volunteer support services across states. Victoria provided the highest level of volunteer support, representing 83.9% of total hours, which was provided by six agencies, followed by New South Wales, which provided 11.8% through seven agencies. The other states and territories did not have a significant paediatric palliative care volunteer support program.

These results indicate that some states and territories use more volunteers than others. The literature suggests there are benefits to be achieved by recruiting and training more voluntary staff to provide non-clinical support to families requiring paediatric palliative care, including home-based respite care.

Profile of registered paediatric palliative care clients

This section presents a description of the paediatric palliative care client base registered for services during 2001–2002.

Paediatric palliative care clients receiving services

One of the key objectives of this survey was to collect data on the paediatric palliative care client base in order to gain a more comprehensive understanding of the numbers of registered clients who received services in 2001–2002. Our preliminary research showed that these services were provided by various agencies across a range of settings. In many instances, agencies provided both adult and paediatric palliative care according to client needs.

Figure 5 shows the proportion of palliative care clients (adult and paediatric) registered for services at responding agencies during 2001–2002. The survey indicated that, at the aggregate level of the responding agencies (n=94 as 31 of the 125 responding agencies did not provide client figures), 94.3% of palliative care services were provided to adult clients while 5.7% were provided to children.

FIGURE 5: PROPORTIONS OF REGISTERED ADULT AND PAEDIATRIC PALLIATIVE CARE CLIENTS WHO RECEIVED SERVICES IN RESPONDING AGENCIES IN 2001–2002

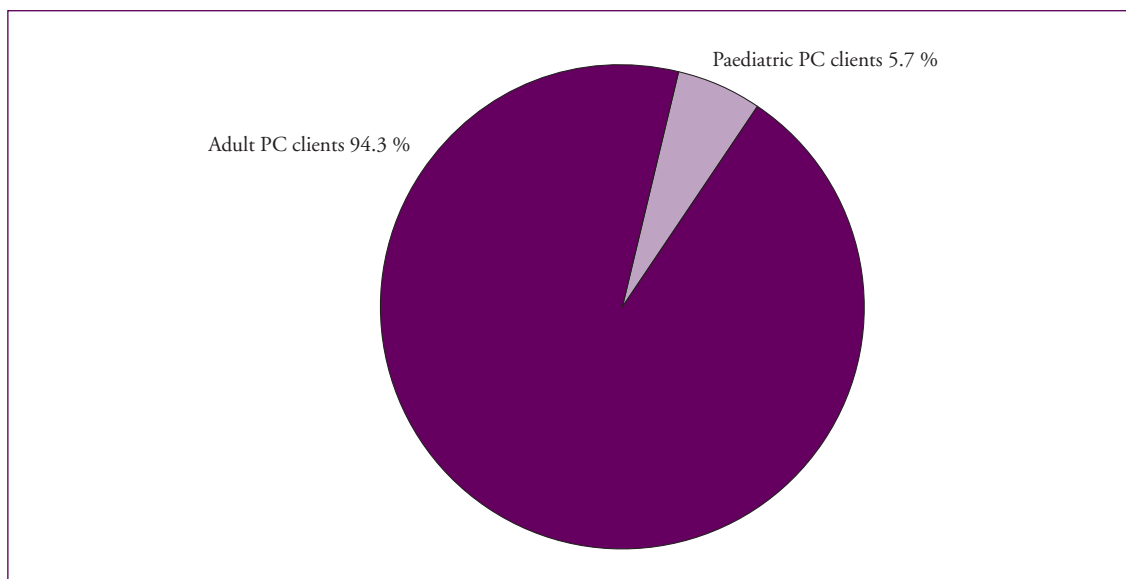


Table 8 shows the proportions of registered adult and paediatric palliative care clients who received services in responding agencies during 2001–2002 on a state and territory basis.

TABLE 8: PROPORTIONS OF REGISTERED ADULT AND PAEDIATRIC PALLIATIVE CARE CLIENTS WHO RECEIVED SERVICES IN RESPONDING AGENCIES IN 2001–2002, BY STATE AND TERRITORY

State or territory	% Adult PC clients	% PPC clients	% PPC clients of national total
ACT	98.8%	1.3%	0.4%
NSW	96.6%	3.4%	25.2%
NT	94.4%	5.6%	1.0%
QLD	95.9%	4.1%	4.1%
SA	97.6%	2.4%	4.5%
TAS	99.6%	0.4%	0.3%
VIC	86.1%	13.9%	58.5%
WA	96.6%	3.4%	6.0%
Total	94.3%	5.7%	100.0%

Table 8 reveals that:

- On a state-by-state basis, the proportion of registered paediatric palliative care clients ranged from 0.3% in Tasmania to 25.2% in New South Wales. Victoria (58.5%) was the only state that provided palliative services to children at the point of diagnosis of a life-threatening condition. In all other states, children were registered with the palliative care agency at the point where they were not undertaking any further treatment.
- Another factor that contributed to the very high Victorian client numbers is the inclusion of families who were registered for bereavement programs (4.5%), which were not provided in other states.

These findings, and a review of documented best practice, indicate that there is an opportunity to improve the integration of paediatric palliative care from the point of diagnosis through to bereavement, to improve both the care provided and client outcomes.

Client condition types

One of the key objectives of the survey was to obtain information about specific client condition types that have been used to classify the conditions of children for the purposes of developing appropriate palliative care responses. For the purposes of the survey, we have used a five-category classification system based on the four patterns of disease progression that have been developed by Goldman (1998) and an additional category determined by the project steering committee of patients who were undergoing continuing curative treatment.

The five client condition categories were:

- conditions for which curative treatments have failed, such as cancers;
- conditions for which intensive treatment may prolong and enhance life, but because of which premature death still occurs, such as cystic fibrosis;
- progressive diseases for which treatment is exclusively palliative, but may extend over many years, such as that for Batten's disease;
- conditions, such as severe cerebral palsy, in which severe neurological problems, although not progressive, lead to vulnerability and increased susceptibility to complications and premature death; and
- other conditions, where patients are undergoing continuing curative treatment.

Question 9 of the survey asked respondents to provide the numbers of registered clients (for whom paediatric palliative care services were provided during 2001–2002) by each of the five condition types, and these data are presented in table 9 (expressed as a percentage of the total number of paediatric palliative care clients in each condition type). For completeness, we have also included the bereavement support program that is provided by Very Special Kids to families in Victoria, though this was not identified on the survey form.

TABLE 9: PROPORTION OF PPC CLIENTS AT RESPONDING AGENCIES IN 2001–2002, BY CONDITION TYPE AND STATE AND TERRITORY

State or territory	% Failed curative	% Treatment to prolong life	% Progressive disease	% Severe neurological	% Continuing curative treatment	% Bereaved families	% Total
ACT	0.6%	0.0%	0.3%	0.5%	0.6%	0.0%	0.4%
NSW	30.9%	24.3%	41.1%	14.0%	23.7%	0.0%	25.2%
NT	1.2%	0.0%	0.3%	3.0%	1.2%	0.0%	1.0%
QLD	7.6%	5.3%	2.4%	6.5%	0.0%	0.0%	4.1%
SA	9.4%	0.0%	5.2%	5.0%	1.2%	0.0%	4.5%
TAS	1.2%	0.0%	0.0%	0.0%	0.0%	0.0%	0.3%
VIC	32.1%	66.4%	48.8%	66.5%	72.3%	100.0%	58.5%
WA	17.0%	3.9%	1.7%	4.5%	1.2%	0.0%	6.0%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Note: Percentages in this table have been rounded up to one significant figure.

These data indicate the following:

- Victoria and New South Wales had the largest proportion of paediatric palliative care clients registered for all five treatment conditions during 2001–2002.
- As previously mentioned, Victoria (Very Special Kids) was the only agency that reported providing paediatric palliative care services to bereaved families. Based on our case study review findings, we understand that providing a holistic support program for bereaved families was unique to this agency. Many agencies providing paediatric palliative care indicated that this was a key area for which insufficient resources were available. In the case of Very Special Kids, the organisation’s successful community fundraising program was able to ensure the availability of resources to provide support services to 168 families.

Costs of providing paediatric palliative care services

This section contains the analysis of costs associated with providing paediatric palliative care services. Our objective was to derive an estimated cost for providing services to clients across each of the five condition categories and to identify the resources utilised in providing these services.

Caveat: We wish to advise that these costs should only be regarded as **indicative** of the resources used by those responding agencies that provided details relating to resource utilisation. As previously advised, we have not extrapolated population-based costs because of the unavailability of population profiles for all service providers. Therefore these costs **do not** represent the total expenditure relating to providing paediatric palliative care.

Estimated total expenditure in 2001–2002

Our survey design processes indicated that a more accurate estimate of expenditure would be achieved if the costs of providing adult palliative care (APC), paediatric palliative care (PPC) and palliative care (PC) could be estimated. The primary reason for this approach was the shortage of information systems at the service provider level. As previously stated, respondents found this question difficult to answer because of a lack of financial management information systems. Twenty-two agencies that provided services to registered paediatric palliative care clients (or 17.6%) were unable to provide a cost estimate. As a result, table 10 shows the estimated proportion of expenditure associated with providing paediatric palliative care services (which should only be regarded as indicative).

TABLE 10: ESTIMATED ADULT AND PAEDIATRIC PALLIATIVE CARE EXPENDITURE IN 2001–2002 AS A PROPORTION OF NATIONAL TOTAL, BY STATE AND TERRITORY

State or territory	APC as % of total \$	PPC as % of total \$	PC as % of total \$
ACT	1.04%	0.02%	1.06%
NSW	37.03%	5.21%	42.23%
NT	1.26%	0.07%	1.33%
QLD	3.22%	0.20%	3.43%
SA	12.70%	0.21%	12.91%
TAS	7.29%	0.04%	7.33%
VIC	15.88%	3.91%	19.78%
WA	11.56%	0.36%	11.92%
Total	89.98%	10.02%	100.00%

Note: Percentages in this table have been rounded up to two significant figures.

A review of table 10 shows the proportion of estimated expenditure associated with providing palliative care services across Australia for 2001–2002, including adult and paediatric care components. From the information provided we can conclude that:

- At the aggregate level, of the total expenditure for providing palliative care services, approximately 90% is related to providing services to adults, while approximately 10% is attributed to providing palliative services to children with life-threatening conditions.
- A comparison of the proportion of paediatric palliative care expenditure across states and territories shows a significant variability, ranging from 5.21% being expended by New South Wales to .02% being expended in the ACT.

Estimated paediatric palliative care unit costs in 2001–2002

Table 11 shows the indicative unit costs of providing adult and paediatric palliative care services for 2001–2002, as reported by responding agencies.

TABLE II: ESTIMATED ADULT AND PAEDIATRIC PALLIATIVE CARE COSTS PER CLIENT FOR RESPONDING AGENCIES IN 2001–2002 BY STATE AND TERRITORY

State or territory	Adult PC clients			Paediatric PC clients			All PC clients		
	Total clients*	Total \$	\$/client	Total clients*	Total \$	\$/client	Total clients*	Total \$	\$/client
ACT	395	\$640,250	\$1,621	5	\$9,750	\$1,950	400	\$650,000	\$1,625
NSW	5,157	\$22,733,760	\$4,408	292	\$3,197,827	\$10,951	5,449	\$25,931,587	\$4,759
NT	151	\$776,238	\$5,141	9	\$42,762	\$4,751	160	\$819,000	\$5,119
QLD	1,186	\$1,978,591	\$1,668	44	\$124,522	\$2,830	1,230	\$2,103,113	\$1,710
SA	2,006	\$7,795,072	\$3,886	58	\$131,585	\$2,269	2,064	\$7,926,657	\$3,840
TAS	746	\$4,476,150	\$6,000	4	\$23,850	\$5,963	750	\$4,500,000	\$6,000
VIC	4,154	\$9,748,538	\$2,347	746	\$2,399,183	\$3,216	4,900	\$12,147,721	\$2,479
WA	2,138	\$7,099,300	\$3,321	73	\$222,640	\$3,050	2,211	\$7,321,940	\$3,312
Total	15,933	\$55,247,899	\$3,468	1,231	\$6,152,118	\$4,998	17,164	\$61,400,018	\$3,577
% Variance unit \$			-3.07%			39.71%			0.00%

* Only records with dollar figures used, so total number of clients does not add up to 22,616.

A review of table 11 suggests that the indicative unit cost estimates support the findings of a number of other research studies that have cited the high costs associated with providing paediatric palliative care services. In summary, these data show that:

- At the national level, the average client cost of providing palliative care services (for adults and children) was \$3,577, while the average cost for a paediatric palliative care client was significantly higher at \$4,998, representing an estimated 40% higher utilisation of resources (estimated salaries and goods and services for 2001–2002).
- The average paediatric palliative care cost per client ranged from \$10,951 in New South Wales to \$1,950 in the ACT. This variability in unit cost across states and territories can be attributed to the accuracy of estimates of service-related costs, and in many cases we believe that these costs have been understated.

Imputation of costs for agencies unable to provide estimated costs of paediatric palliative care expenditure in 2001–2002

An attempt was made to impute the costs for the 22 agencies that were unable to provide expenditure data relating to paediatric palliative care services and this is shown in table 12.

**TABLE 12: IMPUTED COSTS FOR RESPONDING AGENCIES IN 2001–2002
WHERE NO ESTIMATES OF PAEDIATRIC PALLIATIVE CARE EXPENDITURE
COULD BE PROVIDED, BY STATE AND TERRITORY**

State or territory	Total no of agencies	No of agencies nil \$	% Agencies nil \$	Total no of PPC clients	No of PPC clients nil \$	% PPC clients nil \$	Estimated total cost
ACT	1	0	0.0%	5	0	0.0%	\$0
NSW	46	14	11.2%	326	34	2.6%	\$169,920
NT	3	1	0.8%	13	4	0.3%	\$19,991
QLD	18	2	1.6%	53	9	0.7%	\$44,979
SA	10	0	0.0%	58	0	0.0%	\$0
TAS	6	0	0.0%	4	0	0.0%	\$0
VIC	27	2	1.6%	758	12	0.9%	\$59,972
WA	14	3	2.4%	78	5	0.4%	\$24,988
Total	125	22	17.6%	1,295	64	4.9%	\$319,850

Table 12 shows that:

- A total of 22 agencies (17.6%) were surveyed that were not able to provide an estimated cost of paediatric palliative care for a total of 64 clients (4.9%) during 2001–2002.
- After an examination of the types of agencies in this subset, we used the national paediatric palliative care unit cost of \$4,998 for those 64 clients to impute the costs of service provision that have been estimated at a total of \$319,850.

Direct and indirect costs of providing paediatric palliative care services

In order to gain a more comprehensive understanding of the drivers of costs, Q13 in the survey asked agencies to provide estimates of the proportion of direct and indirect expenditure incurred during 2001–2002 in providing paediatric palliative care services. As discussed above, 22 responding agencies were not able to provide information about these costs.

- 1 **Direct expenditure** Direct expenditure was defined as costs expended during 2001–2002 in providing client-related services (for example, nursing salaries and the cost of drugs). Agencies designated the proportion of direct expenditure for each of the five nominated condition types.
- 2 **Indirect expenditure** Indirect expenditure referred to costs that were not specifically client related. The survey asked for proportions of costs associated with a range of indirect service activities, including service coordination, staff support and education, research and fundraising.

Table 13 shows the estimated direct (client-related) expenditure of providing paediatric palliative care services during 2001–2002 as a proportion of the national total.

TABLE 13: DIRECT COSTS OF PROVIDING PAEDIATRIC PALLIATIVE CARE AT RESPONDING AGENCIES IN 2001–2002 AS A PROPORTION OF THE NATIONAL TOTAL, BY CONDITION TYPE AND STATE AND TERRITORY

State or territory	Failed curative	Treatment to prolong life	Progressive disease	Severe neurological	Curative treatment	% Total \$
ACT	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
NSW	15.4%	8.8%	30.0%	2.4%	6.3%	62.7%
NT	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
QLD	0.7%	0.3%	0.3%	0.6%	0.0%	1.9%
SA	1.0%	0.0%	0.3%	0.2%	0.0%	1.4%
TAS	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
VIC	3.7%	5.9%	7.5%	7.0%	7.0%	31.1%
WA	2.4%	0.1%	0.1%	0.1%	0.1%	2.9%
Total direct client-related costs	23.1%	15.1%	38.1%	10.2%	13.4%	100.0%

Note: Excludes costs for 22 agencies and a total of 64 patients. Percentages in this table have been rounded up to two significant figures.

Table 13 reveals the indicative direct expenditure for paediatric palliative care services as follows:

- At the aggregate level, the highest proportion of direct expenditure (38%) related to services to children with progressive disease conditions, followed by 23% of direct costs which were for caring for children with failed curative treatment conditions. These data demonstrate the significantly higher direct costs of supporting clients with conditions that may not be rapidly progressive, but do require extended periods of support.
- There is significant variability in the expenditure levels across states, with New South Wales reporting the highest direct cost of 63%. With respect to the ACT, the Northern Territory and Tasmania, no cost data were provided.

Table 14 shows the estimated costs of providing indirect services to paediatric palliative care clients during the 2001–2002 financial year as a proportion of the national total.

TABLE 14: INDIRECT COSTS OF PROVIDING PAEDIATRIC PALLIATIVE CARE AT RESPONDING AGENCIES IN 2001–2002 AS A PROPORTION OF THE NATIONAL TOTAL, BY TYPE OF SERVICE AND STATE AND TERRITORY

State or territory	Service provider contact	Staff support	Staff education	Research	Fundraising	Other services	% Total \$
ACT	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
NSW	2.8%	3.2%	3.1%	0.0%	4.8%	20.8%	34.7%
NT	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
QLD	0.1%	0.0%	0.1%	0.0%	0.0%	0.8%	1.0%
SA	2.7%	0.4%	0.3%	0.0%	0.1%	0.0%	3.5%
TAS	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
VIC	4.5%	0.9%	1.6%	0.6%	15.2%	35.1%	57.8%
WA	0.8%	0.3%	0.8%	1.0%	0.0%	0.0%	2.9%
% Indirect costs	11.0%	4.8%	5.9%	1.6%	20.1%	56.6%	100.0%

Note: Excludes costs for 22 agencies and a total of 64 patients, and percentages in this table have been rounded up to one significant figure.

Table 14 reveals that the proportional cost of providing indirect services is as follows:

- At the aggregate level, there is significant variability in the proportion of indirect expenditure across states, with Victoria reporting the highest proportion of expenditure at 58%, followed by New South Wales at 35%. With respect to the ACT, the Northern Territory and Tasmania, no costs data were provided.
- Victoria also reported the highest proportion of indirect expenditure with respect to fundraising (15%) and service provider contact (5%).
- The proportion of indirect costs for the various service types also varied. Notably, Victoria expended a high proportion (35%) on ‘other services’ relating to administration, volunteer and hospice services.
- The proportion of costs relating to staff education and training also varied significantly, from 3% being expended in New South Wales to no reported costs for the ACT and others. New South Wales also reported the highest proportion of expenditure (3%) relating to staff support.
- The proportion of expenditure spent on conducting paediatric palliative care research was estimated at 2% of the total indirect costs and this figure was based on the survey data received from Victoria and Western Australia.

Table 15 shows the estimated direct and indirect costs of providing paediatric palliative care services for the 2001–2002 financial year as a proportion of the national total. In addition, because some agencies did not separately report direct and indirect costs, these have been presented in the Unspecified column, totalling \$251,286. For completeness, we have also included an estimate of the cost of the 64 patients from the 22 agencies who did not provide any costs data.

TABLE 15: DIRECT AND INDIRECT COSTS OF PROVIDING PAEDIATRIC PALLIATIVE CARE IN 2001–2002 AS A PROPORTION OF THE NATIONAL TOTAL, BY STATE AND TERRITORY

State	Direct		Indirect		Unspecified direct/ indirect costs		Estimated costs		Total	
	\$	% of Total \$	\$	% of Total \$	\$	% of Total \$	\$	% of Total \$	\$	% of Total \$
ACT	\$0	0.00%	\$0	0.00%	\$9,750	0.15%	\$0	0.00%	\$9,750	0.15%
NSW	\$2,489,977	38.47%	\$670,061	10.35%	\$37,789	0.58%	\$169,920	2.63%	\$3,367,747	52.04%
NT	\$0	0.00%	\$150	0.00%	\$42,612	0.66%	\$19,991	0.31%	\$62,753	0.97%
QLD	\$74,114	1.15%	\$19,907	0.31%	\$30,500	0.47%	\$44,979	0.69%	\$169,501	2.62%
SA	\$56,858	0.88%	\$67,592	1.04%	\$7,135	0.11%	\$0	0.00%	\$131,585	2.03%
TAS	\$0	0.00%	\$0	0.00%	\$23,850	0.37%	\$0	0.00%	\$23,850	0.37%
VIC	\$1,233,245	19.06%	\$1,116,288	17.25%	\$49,650	0.77%	\$59,972	0.93%	\$2,459,155	38.00%
WA	\$115,846	1.79%	\$56,794	0.88%	\$50,000	0.77%	\$24,988	0.39%	\$247,628	3.83%
Total	\$3,970,040	61.34%	\$1,930,792	29.83%	\$251,286	3.88%	\$319,850	4.94%	\$6,471,969	100.00%

Note: Percentages in this table have been rounded up to two significant figures.

Table 15 provides an insight into the component direct and indirect costs of paediatric palliative care service provision for 2001–2002 as follows:

- The estimated national total cost of service delivery was \$6.472 million.
- At the national level, the direct patient-related costs were 61% of total estimated expenditure and indirect costs were 30%.
- By using the costs of care in table 12, we calculated that New South Wales (38%) expended \$2.490 million, which was the highest level of resource use for direct client-related costs, while Victoria incurred the highest level of expenditure for indirect costs of \$1.116 million (17%).
- To obtain a more accurate cost of services provided, a cost estimate for the 64 clients for whom financial data were not provided was based on the national average direct cost per paediatric patient, which this study calculated at \$4,998 (see table 11). Using this approach, the imputed total cost of providing care to these clients was \$319,850.

Range and type of paediatric palliative care services

A range of services was provided to children who have life-limiting conditions and their families. In Q6 of the survey we were interested in gaining a better understanding of the types and volume of services provided across Australia. Table 16 shows the proportion of the types of services (by % volume of activity) offered on a state and territory basis. Five responding agencies did not provide information about this question.

TABLE 16: RANGE OF PAEDIATRIC PALLIATIVE CARE SERVICES OFFERED IN 2001–2002 BY TYPE OF SERVICE, AND STATE AND TERRITORY

Service type	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	% of national total
Emotional support	0.10%	3.70%	0.21%	1.54%	0.92%	0.51%	2.16%	1.23%	10.37%
Symptom control	0.10%	4.00%	0.10%	1.44%	0.92%	0.31%	2.05%	1.13%	10.06%
Community-based services	0.10%	4.00%	0.21%	1.33%	1.03%	0.41%	2.16%	0.72%	9.96%
Information	0.10%	3.49%	0.21%	1.44%	0.92%	0.41%	2.26%	1.03%	9.86%
Bereavement care	0.10%	3.08%	0.10%	1.33%	1.03%	0.31%	2.05%	1.13%	9.14%
Volunteer support	0.10%	2.26%	0.31%	0.82%	0.51%	0.51%	2.05%	0.92%	7.49%
Family support	0.10%	1.64%	0.21%	1.13%	0.72%	0.41%	1.44%	0.82%	6.47%
Community liaison	0.00%	1.85%	0.21%	0.92%	0.82%	0.31%	1.85%	0.51%	6.47%
Case management	0.10%	1.44%	0.10%	0.82%	0.92%	0.31%	1.54%	0.92%	6.16%
Respite	0.00%	1.03%	0.21%	1.44%	0.72%	0.21%	0.92%	1.13%	5.65%
Hospital-based	0.00%	1.75%	0.10%	0.72%	0.41%	0.31%	0.92%	0.82%	5.03%
Sibling support	0.10%	0.62%	0.10%	0.82%	0.21%	0.31%	1.13%	0.62%	3.90%
Hospice	0.00%	0.62%	0.00%	0.51%	0.31%	0.31%	0.31%	0.62%	2.67%
Outreach	0.00%	0.72%	0.00%	0.51%	0.31%	0.10%	0.51%	0.51%	2.67%
Adjuvant therapy	0.00%	0.31%	0.10%	0.51%	0.31%	0.31%	0.51%	0.41%	2.46%
Other services	0.10%	0.21%	0.00%	0.62%	0.21%	0.00%	0.51%	0.00%	1.64%
% of total state or territory									
PC services	1.03%	30.70%	2.16%	15.91%	10.27%	5.03%	22.38%	12.53%	100.00%

Table 16 provides an indication of the spread of paediatric palliative care service types on a state-by-state basis. In summary, the situation was:

- At the aggregate level, the greatest proportions of services were for providing emotional support, symptom control, community-based services and information, representing approximately 40% of total services.
- Providing outreach, sibling and respite services (12%) took up a considerably lower proportion of the whole, which supports the findings of previous research studies that have shown there is a need to develop these services further.
- In some states or territories (for example, the Northern Territory, the ACT and Tasmania), the level of service availability is significantly lower than in the others, which may mean a high level of unmet client need or that there are fewer children requiring paediatric palliative care.

Resources used in providing types of paediatric palliative care services

Question 14 of the survey asked agencies to identify the proportion of their total expenditure used in providing palliative care services during 2001–2002. These proportions were used to estimate the cost of providing services for each of the 14 service types. Table 17 shows the results of the analysis.

TABLE 17: ESTIMATED PROPORTION OF RESPONDING AGENCIES' TOTAL COSTS USED FOR PROVIDING PPC SERVICES IN 2001–2002, BY SERVICE TYPE AND STATE AND TERRITORY

Service type	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	% total
Hospice		51.9%		1.1%			11.6%		31.5%
Respite services		29.2%	0.4%	0.7%			36.3%	3.8%	29.5%
Family support	5.0%	0.0%		26.2%	6.8%	20.0%	22.2%	4.0%	9.6%
Symptom control	10.0%	4.9%		5.6%	12.8%		2.0%	31.0%	4.8%
Not stated		2.4%	99.6%		11.3%		3.2%	22.5%	4.3%
Bereavement care	10.0%	1.4%		4.0%	13.6%	20.0%	5.3%	10.9%	3.7%
Emotional support	10.0%	4.6%		12.4%	7.2%		1.5%	8.8%	3.7%
Other services	5.0%			8.9%	0.1%		6.3%		2.6%
Community-based services	40.0%	1.4%		25.8%	8.5%	20.0%	2.4%	0.4%	2.5%
Community liaison		0.7%		1.2%	3.6%	10.0%	3.8%	3.6%	2.1%
Hospital-based services		1.4%		1.2%	25.4%		1.4%	3.5%	2.0%
Information provision	5.0%	0.8%		1.9%	5.3%	10.0%	1.7%	4.0%	1.4%
Sibling support	5.0%	0.0%		8.1%		20.0%	1.4%	3.6%	0.9%
Case management	10.0%	0.1%		1.6%	5.6%		0.8%	4.0%	0.7%
Adjuvant therapy		1.2%		1.1%			0.2%		0.7%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Table 17 shows that:

- At the aggregate level, the highest proportion of total cost (31.5%) in the survey was attributed to hospice services provided by Bear Cottage in New South Wales, Very Special Kids in Victoria and Zoe Reed's Little Bridge House in Queensland. It is important to note that the funding for these services is ostensibly provided through private fundraising.
- Respite care took 29.5% of total resources, with New South Wales and Victoria reporting the highest expenditures in this area, of 29.2% and 36.3% respectively. Once again, these costs are primarily attributed to the services provided by Bear Cottage and Very Special Kids.
- The proportion of resources associated with providing bereavement care (3.7%), and emotional (3.7%) and sibling support (0.9%) were significantly lower. These findings are similar to those of other studies undertaken in the UK and the USA.

Accessibility to other clinical services

One of the key issues raised by previous research studies about providing paediatric palliative care is the importance of meeting the needs of clients with regard to the accessibility of a range of clinical services. Question 16 in the survey was designed to identify the availability of these clinical services. Table 18 shows the profile of the types of clinical services involved in supporting families with children who had life-limiting conditions across Australia.

TABLE 18: PROPORTION OF NATIONAL CLINICAL SERVICES USED BY RESPONDING PAEDIATRIC PALLIATIVE CARE AGENCIES IN 2001–2002, BY STATE AND TERRITORY

Clinical service type	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Total	Total agencies with access	Total agencies with no access
General practitioners	1.0%	39.0%	2.0%	15.0%	8.0%	5.0%	18.0%	12.0%	100.0%	80.0%	20.0%
Social workers		42.9%	3.6%	11.9%	9.5%	6.0%	15.5%	10.7%	100.0%	67.2%	32.8%
Occupational therapists		37.8%	3.7%	12.2%	11.0%	4.9%	18.3%	12.2%	100.0%	65.6%	34.4%
Physiotherapists		33.3%	3.7%	12.3%	11.1%	4.9%	21.0%	13.6%	100.0%	64.8%	35.2%
Registered nurse		34.2%	2.6%	14.5%	10.5%	7.9%	17.1%	13.2%	100.0%	60.8%	39.2%
Paediatrician	1.4%	35.2%	4.2%	15.5%	8.5%	8.5%	18.3%	8.5%	100.0%	56.8%	43.2%
Palliative physician	1.4%	40.0%	1.4%	14.3%	7.1%	7.1%	20.0%	8.6%	100.0%	56.0%	44.0%
Other allied health staff		35.9%	3.1%	14.1%	9.4%	6.3%	18.8%	12.5%	100.0%	51.2%	48.8%
Mental health workers	1.6%	35.5%	3.2%	16.1%	9.7%	6.5%	16.1%	11.3%	100.0%	49.6%	50.4%
Oncologist	1.7%	33.3%	3.3%	20.0%	10.0%	6.7%	20.0%	5.0%	100.0%	48.0%	52.0%
Psychologist	1.7%	29.3%	5.2%	15.5%	10.3%	6.9%	20.7%	10.3%	100.0%	46.4%	53.6%
Pain management specialist		35.1%	3.5%	12.3%	8.8%	8.8%	19.3%	12.3%	100.0%	45.6%	54.4%
Paediatric palliative care nurse		34.6%	3.8%	13.5%	7.7%	5.8%	28.8%	5.8%	100.0%	41.6%	58.4%
Paediatric oncologist		36.0%	4.0%	12.0%	10.0%	8.0%	20.0%	10.0%	100.0%	40.0%	60.0%

Table 18 also indicates the proportions of agencies that did and did not have access to the specific clinical services needed by families who require paediatric palliative care. In summary, the following conclusions can be made:

- At the aggregate national level, the most accessible service, identified by 80% of responding agencies, was that provided by general practitioners.
- Over 50% of the responding agencies indicated that they had no access to mental health workers, oncologists, psychologists, pain management specialists, paediatric palliative care nurses and paediatric oncologists.

- These findings support the results of other studies undertaken in the area of paediatric palliative care and indicate that improved integrated models of care and specific education and training programs must be developed to ensure the availability of appropriate clinical services to paediatric palliative care clients.

In summary, the results of the analysis of survey costs have shown that there are inadequate data to show how the way care is provided and its associated costs may impede efforts to deliver effective services, educate health professionals and design appropriate health services policies for paediatric palliative care.

Ability to meet client needs

Our review of the literature on models of paediatric palliative care has shown that the focus of these models has been on providing integrated and holistic services tailored to meet individual family needs and based on clinical best practice. One of the objectives of the survey was to find out from service providers what they saw as the main areas of unmet need. Question 18 in the survey was designed to identify the degree to which service providers were able to meet the needs of their paediatric palliative care clients.

Extent to which client needs are being met

Table 19 shows the proportion of agencies that were able and unable to meet the needs (including clinical, psychological and spiritual) of their clients.

TABLE 19: PROPORTIONS OF RESPONDING AGENCIES ABLE AND UNABLE TO MEET CLIENT NEEDS IN 2001–2002, BY STATE AND TERRITORY

State or territory	Unable to meet client needs	Partially able to meet client needs	Able to meet all client needs	Unanswered	Total
ACT			100.0%		100.0%
NSW	2.2%	80.4%	4.3%	13.0%	100.0%
NT		66.7%	33.3%		100.0%
QLD	5.6%	38.9%	50.0%	5.6%	100.0%
SA	20.0%	50.0%	20.0%	10.0%	100.0%
TAS		83.3%	16.7%		100.0%
VIC		59.3%	11.1%	29.6%	100.0%
WA		71.4%	14.3%	14.3%	100.0%
Total	3.2%	65.6%	16.8%	14.4%	100.0%

Note: Percentages in this table have been rounded up to one significant figure.

Table 19 indicates that:

- At the aggregate level, 16.8% of agencies indicated that they were able to meet their client needs, while the vast majority (65.6%) indicated that the needs of clients were only being partially met, and 3.2% of agencies reported that they were unable to meet client needs. Of the responding agencies, 14.4% did not answer the question.

- A review of the results of this analysis on a state-by-state basis shows that, apart from the ACT, the proportion of agencies able to meet all their clients' needs is low and ranges from 50% of agencies in Queensland to 4.3% of agencies in New South Wales.

These results indicate the need for additional resources for providing paediatric palliative care services to increase the availability of those services and meet client needs.

Reasons client needs are not being met

Question 19 in the survey addressed the prevailing reasons that service providers were not able to meet the needs of families caring for children with life-threatening conditions. Table 20 below provides a summary of the key reasons, based on service catchment area.

TABLE 20: REASONS RESPONDING AGENCIES DID NOT MEET CLIENT NEEDS IN 2001–2002, BY CATCHMENT AREA

Reason needs not met	Catchment area					Total
	Local	Regional	Statewide	Other	No answer	
Few clients/low referrals — lack of experience	13.3%	10.6%	0.0%	0.0%	0.9%	24.8%
Lack/unavailability of (professional) support	8.8%	12.4%	4.4%	2.7%	0.0%	28.3%
Lack of resources/funding	5.3%	4.4%	2.7%	1.8%	0.0%	14.2%
New service	0.9%	0.0%	0.0%	0.9%	0.0%	1.8%
Lack of education and/or training	0.0%	2.7%	0.0%	0.0%	0.0%	2.7%
Remote location	5.3%	6.2%	0.0%	0.0%	0.0%	11.5%
Services provided/accessed through other organisations	8.8%	4.4%	0.0%	2.7%	0.9%	16.8%
Total	42.5%	40.7%	7.1%	8.0%	1.8%	100.0%

Note: Percentages in this table have been rounded up to one significant figure.

Table 20 reveals that:

- At the national level, 24.8% of all respondents, 53.6% of which were local providers, were unable to meet clients' needs because of low client referral numbers, which meant that staff lacked experience and skills in providing specialist paediatric palliative care. Other reasons cited included the remoteness of the location of clients (11.5%), having to access services through other organisations, which indicates problems with service coordination (16.8%), and lack of resources (14.2%).
- Of the 40.7% of agencies with responsibility for providing regional services, the problems of unmet need were attributed to lack of education/training, geographic isolation of clients, lack of professional support, and lack of experience because of low referral numbers.
- The specialist children's hospitals (7.1%) responsible for providing statewide services identified their reasons for unmet need as lack of resources and lack of professional support staff.
- Other services (for example, local government, 8%) reported that their reasons for not meeting clients' need were associated with having to access services through other organisations and low numbers of client referrals.

Table 21 analyses the reasons agencies did not meet need based on whether they provided a hospital service, a community-based service or a joint hospital and community-based service.

TABLE 21: REASONS RESPONDING AGENCIES DID NOT MEET CLIENT NEEDS IN 2001–2002, BY KIND OF SERVICE

Reason care not met	Service base					Total
	Hospital	Community	Hospital & community	Other services	Unanswered	
Few clients/low numbers of referrals, lack of experience	3.6%	57.1%	35.7%	3.6%	0.0%	100.0%
Lack/unavailability of (professional) support	12.5%	40.6%	34.4%	9.4%	3.1%	100.0%
Lack of resources/funding	12.5%	43.8%	37.5%	0.0%	6.3%	100.0%
New service	0.0%	50.0%	0.0%	50.0%	0.0%	100.0%
Lack of education and/or training	0.0%	33.3%	66.7%	0.0%	0.0%	100.0%
Remote location	7.7%	46.2%	38.5%	7.7%	0.0%	100.0%
Services provided/accessed through other organisations	15.8%	52.6%	31.6%	0.0%	0.0%	100.0%
Total	9.7%	47.8%	35.4%	5.3%	1.8%	100.0%

Table 21 indicates that:

- Hospital-based service providers reported problems predominantly related to the lack of professional support and funding resources, and to accessing services through other service providers.
- Of all responding agencies, those providing community-based services (47.8%) appeared to have the greatest problem in meeting the needs of clients, with high proportions of these agencies (ranging from 57% to 33%) identifying problems in all seven of the areas in the table. These results also suggest that community-based service providers require additional support when establishing new services.
- The reasons cited by agencies responsible for both hospital and community services (35.4%) for not meeting clients' needs were similar to those reported by community-based services, except that the establishment of new agencies was not cited as an issue.

In summary, the results of the analysis of unmet client needs suggests that there is a need to develop a framework (based on evidence-based best practice) to support the provision of competent clinical services across the continuum of care. This should be done by developing nationally agreed protocols that focus on coordination, continuity of care and providing support and information to service providers across care sites, including hospitals and community service providers.

Conclusion

Overall, the analysis suggests that the survey has produced a valuable source of new data about the profile of services provided to children with life-limiting conditions and their families in Australia. We acknowledge that the survey was not undertaken on the basis of obtaining full enumeration, and that complete population estimates could not be calculated.

We also acknowledge that, based on the numbers of telephone queries received from agencies completing the survey form, answering the survey questions proved to be an onerous task for many, because they lacked systems for providing information on types of services delivered, types of clients for whom services were provided, and resources utilised in service provision. Where quantifiable information was not available, agencies were advised to make estimates, which were clearly subjective.

We also acknowledge that a small proportion of responding agencies were unable to provide answers to a number of the questions about resource utilisation, the range of services provided and unmet needs. Nevertheless, in analysis, the coverage level achieved by the survey process (in terms of the numbers of agencies responding and the relative internal consistency of the data) suggests that the survey results are indicative of what happens in practice.

The survey has produced a series of important findings that are summarised as follows:

- comprehensive paediatric palliative care services are required for children with life-limiting conditions who live in rural areas;
- existing models of care should be reviewed to ensure that more innovative models of care are implemented that will improve the accessibility of services to families requiring paediatric palliative care support after business hours;
- models of care in all states should be able to provide an agreed minimum level of paediatric palliative care support to families who have children with life-limiting conditions;
- additional resources are required to provide comprehensive bereavement support, respite care and sibling support in all state and territory jurisdictions;
- evidence-based best practice indicates that additional resources are required to employ qualified paediatric palliative care medical and nursing staff, mental health workers, psychologists and pastoral care staff to ensure that a comprehensive paediatric palliative care service is provided;
- additional resources are required for the recruitment and training of volunteer staff to provide non-clinical support to families requiring paediatric palliative care, including home-based respite care if required;
- documented best practice indicates that there is an opportunity for integrating palliative care from the point of diagnosis through to bereavement to improve both the care provided and client outcomes;
- there are inadequate data to show how the way care is provided and its associated costs may impede efforts to deliver effective services, educate health professionals and design appropriate health services policies for paediatric palliative care;
- improved integrated models of care and specific education and training programs should be developed to ensure the availability of appropriate clinical services to meet the needs of paediatric palliative care clients; and
- in order to help agencies meet the needs of clients, a framework should be developed (based on evidence-based best practice) to support the provision of competent clinical services across the continuum of care according to nationally agreed protocols. These should focus on coordination, continuity of care and providing support and information to service providers across care sites, including hospitals and community service providers.

Chapter 5

Case study review



This chapter provides a summary of our findings in the case study reviews of 15 agencies that provided palliative care services to children with life-threatening conditions and their families.

Case study review objectives

In order to gain a comprehensive understanding of the provision of paediatric palliative care services, we invited 15 agencies, located in metropolitan and rural areas across Australia, to participate as case study sites. These agencies were selected on the basis of the information they provided as part of the national survey of palliative care services. We conducted site visits to each of these palliative care agencies and consulted with funders, policy makers, service providers, volunteers and representatives of linked services. These discussions focused on structural and operational aspects of service delivery, issues affecting service delivery, and barriers to and opportunities for service improvement. The information collected provided us with the basis on which to analyse good and best practice service delivery models and to formulate ideas for future development.

Case study sample

The case study sample was selected on the basis of information provided by analysing the survey responses and through discussions with state health departments and palliative care associations. The case study sample included specialist paediatric palliative care services and adult palliative care services that provided services to paediatric clients during 2001–2002. In addition, we structured the case study sample to include agencies that provided services to clients across four different life-threatening conditions:

- failed curative treatment (for example, cancers);
- treatment to prolong life (for example, cystic fibrosis);
- progressive diseases (for example, Batten's disease); and
- severe neurological conditions (for example, cerebral palsy).

The purpose of the case studies was to collect detailed information from these services relating to the specific paediatric palliative care models that have been implemented. Data collected through the case study process have been used to map the paediatric palliative care services currently available for clients across the four life-threatening illness groups, taking into account cultural and geographic differences. The 15 case study sites were selected to provide a representation of both metropolitan and rural palliative care agencies (see below list).

State or territory	Metropolitan PPC agency	Regional PPC agency
New South Wales	<ul style="list-style-type: none"> the Children's Hospital at Westmead, and Bear Cottage Sydney Children's Hospital, Palliative Care Service 	<ul style="list-style-type: none"> Lismore Palliative Care Service
Victoria	<ul style="list-style-type: none"> Victorian Paediatric Palliative Care Program (Royal Children's Hospital) Very Special Kids 	<ul style="list-style-type: none"> Ballarat Hospice Care
Queensland	<ul style="list-style-type: none"> Royal Children's Hospital, Brisbane Zoe Reed Little Bridge House 	<ul style="list-style-type: none"> Townsville Palliative Care Service
South Australia	<ul style="list-style-type: none"> the Women's and Children's Hospital 	<ul style="list-style-type: none"> Port Augusta and Regional Palliative Care Service
Western Australia	<ul style="list-style-type: none"> Princess Margaret Hospital 	<ul style="list-style-type: none"> Peel Community Health
Australian Capital Territory	<ul style="list-style-type: none"> the Canberra Hospital 	
Tasmania		<ul style="list-style-type: none"> Tasmanian Palliative Care Service, Launceston General Hospital

Case study framework

An analytical framework was developed that addressed specific issues in a systematic way, ensuring that data were collected in a manner that was consistent enough to enable the analysis of case study information, with an emphasis on:

- analysing the paediatric palliative care models that are in operation across the 15 agencies with respect to the four life-threatening illness conditions;
- analysing the variations in service delivery across the 15 agencies;
- identifying any gaps in the existing paediatric palliative care models and areas of unmet client need;
- identifying any barriers to effective and integrated patient-centred service delivery;
- identifying the extent to which paediatric palliative care services are in accord with evidenced-based best practice; and
- identifying the opportunities to improve the efficiency, effectiveness and quality of the delivery of paediatric palliative care programs.

Discussion framework

The case study fieldwork involved visits to each of the 15 agencies to consult with funders, policy makers, service providers, volunteers and representatives involved in providing palliative care services. The focus of these discussions was on the existing service model. Key issues that were addressed during these visits were:

- 1 the current service delivery model, including:
 - the history of service development;
 - the key features of the model, including the elements that were considered to be the most effective;
 - gaps in service delivery; and
 - the strategies used to reduce those gaps.
- 2 the current service plan, including:
 - the program's vision and objectives;
 - the range of services and costs, the client mix and other service development initiatives (for example, respite care, research and home-based services) that have been implemented; and
 - service improvement.
- 3 the current funding arrangements, including:
 - the appropriateness of existing funding for meeting service needs; and
 - the key issues affecting funding and resource allocation.
- 4 staffing issues, including:
 - those affecting service delivery;
 - staff training requirements; and
 - opportunities for addressing these staffing needs.
- 5 performance measurement mechanisms, including initiatives to improve performance measurement.
- 6 the clinical and supportive aspects of care, including:
 - the availability of multidisciplinary services;
 - the availability of the key paediatric palliative care services (for example, pain management, symptom control, respite care, hospice care, bereavement care and family, sibling and emotional support);
 - the key clinical and support issues; and
 - opportunities for improving clinical and supportive care.
- 7 areas of unmet need, including opportunities for satisfying unmet need.
- 8 links between service providers, including:
 - the effectiveness of links between service providers across the acute and community health sectors;
 - the barriers and gaps to service integration; and
 - opportunities for improving links across service providers.

- 9 the coordination of care, including:
 - the effectiveness of service coordination;
 - the evidence of case management, client follow-up and support mechanisms;
 - the barriers to care coordination; and
 - opportunities for improving care coordination.
- 10 the access of disadvantaged groups to services, including those from non-English-speaking backgrounds and Indigenous families, and also families from rural and remote regions, including:
 - the availability of culturally sensitive services;
 - the barriers to providing services to this group of clients; and
 - opportunities for improving service delivery to these target groups.
- 11 general practitioners, including:
 - the role of general practitioners in the service delivery system;
 - the issues affecting continuity of care and integration; and
 - opportunities for improving links between general practitioners and service providers, and integrating services to support family needs.
- 12 volunteer support services, including:
 - the availability of volunteer support services;
 - the key issues affecting the provision of volunteer support services;
 - these services' ability to meet client needs; and
 - opportunities for improving volunteer support services.
- 13 communication and information dissemination, including:
 - the mechanisms for communicating information about paediatric palliative care services;
 - the key issues affecting communication and information dissemination; and
 - opportunities for improving communication and information dissemination.
- 14 the strategies for modifying current service models, including the strategies that can be implemented to modify current services and outcomes on the basis of evidence-based best practice.
- 15 alternative service delivery models, including:
 - the major factors affecting the implementation of these models; and
 - the implications of implementing these models.

A summary of the key findings of our review of these 15 case studies is shown below.

Summary of current paediatric palliative care models

Based on our review of the 15 case study sites, table 22 below provides a summary of the key operational features of these paediatric palliative care models.

TABLE 2.2: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Children's Hospital Westmead (CHW) and Bear Cottage (BC), New South Wales	2001 — Bear Cottage Children's Hospice	<ul style="list-style-type: none"> PPC provided through network of services with CHW and BC — viewed as a state, national and international resource. CHW operates as a consulting and liaison service to hospital departments on a referral basis. CHW conducts regular PPC meetings to provide a forum for discussing the domains of care available and identifying desired outcomes. CHW's clinical nurse consultant (CNC) provides care coordination that includes liaison with wards, departments, community services and schools, and education of families. BC provides clinical care, school for patients and siblings, accommodation for families, respite for families and children's hospice services. 	<ul style="list-style-type: none"> Integrated statewide PPC service. Regular communication with all service providers. Focus on effective leadership, teamwork and innovation in delivering PPC services. Commitment to striving for excellence in clinical care, research, teaching and advocacy. Provision of consultancy and liaison service to health care professionals across New South Wales. 	Available	<ul style="list-style-type: none"> Lobbying state and federal departments of health for additional funding for PPC. Continuing the development of an integrated PPC service to ensure a seamless system of home, hospital and hospice care, and a management structure facilitating the integration of and stronger links between PPC providers. Continuing the development of home, hospice and hospital-based services based on best practice model outcomes. Providing clinical care to clients utilising evidence-based approaches to palliative care management. Focusing on developing a culture of education, research and inquiry. Developing a child and family-focused bereavement program that is available statewide. Improving services to the disadvantaged population.

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Sydney Children's Hospital, New South Wales	1995	<ul style="list-style-type: none"> Operates to a consultancy and liaison model with patients remaining under the care of a primary paediatrician. PPC paediatrician and CNC work with primary clinical teams to provide support to families. Bereavement position in oncology. PPC paediatrician, in consultation with treating physicians, liaises with general practitioners and local paediatricians and provides education and support. PPC CNC coordinates care needs and supports local service providers, generalist PC services and schools. Social work staff from clinical departments in the hospital work collaboratively with PPC team to provide services. Extensive referral network. Collaboration with Prince of Wales Hospital to ensure appropriate pain management. 	<ul style="list-style-type: none"> Early identification of children who may benefit from PPC is required. Partnerships and links with other community service providers are promoted. Education, training and assistance provided for service providers. Information provided to care providers. Consultancy and liaison service provided to community health care professionals. 	<p>Incorporated in south-eastern Sydney area palliative care plan</p>	<ul style="list-style-type: none"> Implementing a comprehensive bereavement care program. Developing strategies to facilitate earlier referral of children to PPC services. Improving the access and equity of available PPC support services for children with non-malignant life-threatening conditions. Developing a national PPC database to facilitate research into evidence-based practice models. Investigating admitting rights to Bear Cottage to provide improved access to the facility.

TABLE 2.2: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002 (CONT)

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
St Vincent's Hospital Palliative Care Service, Lismore, New South Wales	Not available	<ul style="list-style-type: none"> • PC service for adults and children. • A focus on curative treatments provided by specialist hospitals in Brisbane. • Multidisciplinary palliative care services. • 24-hour telephone support service. • Some after-hours back-up care available. • Volunteer support services available. • Limited home and facility respite, psychology and social work services. • Regular liaison with general practitioners to provide quality care. 	<ul style="list-style-type: none"> • Established network incorporating other service providers and the community. • Focus on tailoring resources and services to meet the needs of clients. • Bereavement support group. 	Adult palliative care plan available	<ul style="list-style-type: none"> • Improving service integration, including establishing volunteer coordinator structure, and providing additional funds for community nursing teams when service demands are high. • Improving access and equity, including progressively establishing a 24-hour, two-day-a-week community-based multidisciplinary service, increasing service access for the Aboriginal community and improving access to transport for patients, families and carers. • Introducing quality evaluation and improvement, including developing an area-wide data collection and information system. • Developing area palliative care policies and procedures aimed at receiving earlier referrals. • Providing education and information, including ongoing education for nurses and general practitioners, and developing strategies focusing on information and training for the community.

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Victorian Paediatric Palliative Care Program (VPPCP), Victoria	2000	<ul style="list-style-type: none"> Operates on a consultancy and liaison model. Framework committed to equity of access for all life-threatening condition types. Extensive referral network. Partnership with Very Special Kids and Monash Medical Centre. Medical case management. Active early intervention to support clients. 	<ul style="list-style-type: none"> Early identification of children who may benefit from PPC. Partnerships and links with other community service providers are promoted. Education, training and assistance given to service providers. Information provided to care providers. Consultancy and liaison service provided to community health care professionals. 	Available	<ul style="list-style-type: none"> Improving acute sector work relationships to improve service referrals. Providing additional tertiary-based education programs (undergraduate and postgraduate courses). Developing leadership programs linking interested PPC providers to increase awareness and provide staff development opportunities. Providing more regional services and those for people with culturally or linguistically diverse backgrounds. Developing a national PPC database to facilitate research into evidence-based practice models.
Very Special Kids, Victoria	1984	<ul style="list-style-type: none"> Operates on a holistic model. Comprehensive family support services. Family-centred services. Partnership with VPPCP and Monash Medical Centre. A children's hospice. 	<ul style="list-style-type: none"> Multidisciplinary approach to planning and service delivery. Coordinated service based on a community partnership. Model underpinned by evidence-based best practice and quality standards. Information provided via newsletters, letters and phone linkups. Counselling support for child, siblings, parents and other family members. 	Available	<ul style="list-style-type: none"> Increasing awareness of and education in the role of PPC and formalising partnerships. Increasing research and education. Increasing regional services and those for people with culturally or linguistically diverse backgrounds. Promoting benchmarking activities.

TABLE 2.2: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002 (CONT)

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Ballarat Hospice Care, Victoria	1993	<ul style="list-style-type: none"> • PC service for adults and children. • Multidisciplinary palliative care services. • Client/family-focused services. • Both logistical and financial support for families. • Weekly meetings held with other service providers. • Regular liaison with general practitioners to improve discharge planning and continuity of care for clients. • Strong link with Very Special Kids. 	<ul style="list-style-type: none"> • Established network incorporating other service providers and the community. • Focus on tailoring resources and services to meet the needs of clients. • Value for money service. • Symptom and bereavement management services. 	None available for PPC	<ul style="list-style-type: none"> • Developing an awareness program for health professionals and the community. • Accessing additional funding and sponsorship for specific projects to improve service delivery. • Building relationships with other service providers. • Undertaking specific staff development programs. • Increasing the profile of paediatric palliative care in the community.
Oncology Department, Royal Children's Hospital (RCH), Brisbane, Queensland	Operates a PPC case management model for oncology patients.	<ul style="list-style-type: none"> • The oncology unit provides educational and clinical resources for paediatric oncology palliative care patients. • Paediatric oncology palliative care outreach nursing service. • Local paediatricians, general practitioners and domiciliary nurses provide primary care, with the outreach service providing a consultative support. • 24-hour phone support and home visits to patients within a 30-minute drive of RCH. • Inpatient respite and pain control. • Focus on working with both the patient and siblings. 	<ul style="list-style-type: none"> • Case management model enhances arrangement and delivery of services. • Strong links with community-based services. • Strong, supportive links between families and the hospital. 	PPC strategic plan not available	<ul style="list-style-type: none"> • Developing an integrated, statewide PPC service based on best practice approaches. • Obtaining additional funding to support service operations, including respite and bereavement care, medical supplies and equipment purchases. • Improving support services provided for bereavement care and sibling support. • Increasing training for medical and other health care professions about the role and provision of PPC. • Improving access to PPC services for patients with non-malignant life-threatening conditions. • Developing a national database that can be used to plan PPC services, allocate resources and undertake research into improved models of care.

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Zoe Reed Little Bridge House, Queensland	1994	<ul style="list-style-type: none"> • Volunteer-based service with a family focus. • Plans to begin building a purpose-built respite and hospice facility in 2003. • Service philosophy is that PPC has a role in supporting children and families from the time of diagnosis of a life-limiting condition, through the end-of-life stage, to bereavement. • Operates with a community focus and is reliant on support and financial assistance from local businesses and organisations. • Various outreach family support services provided to families whether the child is at home or in hospital care. • Referrals for outreach family support services come from Karuna Hospice Service, Montrose Access and the Royal Children's Hospital. 	<ul style="list-style-type: none"> • Volunteer training programs. • Family support training programs. • Specialist in the field of paediatric palliative care. • Access to cars so that volunteers can travel to clients. • Home-based respite services. • Outreach services that allow parents and siblings to meet others and share experiences. 	<p>Service plan available</p> <ul style="list-style-type: none"> • Completing facility to provide for a central point for respite, hospice, outreach and volunteer services. • Increasing client base after facility construction. • Providing a statewide hospice and respite service for Queensland similar to the Very Special Kids model. 	

TABLE 22: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002 (CONT)

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Townsville Paediatric Palliative Care Service, Queensland	1987	<ul style="list-style-type: none"> Provides PC services to adults and children through a multidisciplinary team approach throughout the northern zone in Queensland. Consultation with hospitals and community-based service providers. PC education for service providers and community groups. PC team coordinates services for home nursing, home help and hire of equipment. Bereavement, emotional, social and psychological support for children and families. 	<ul style="list-style-type: none"> Established network incorporating other service providers and the community. Resources and services tailored to meet the needs of clients. Service providers educated in PPC. 	PC strategic plan for Queensland has been developed	<ul style="list-style-type: none"> Improving equity and access to PPC services in the setting of choice. Developing ongoing shared-care partnerships with service providers. Improving continuity of care and service integration. Implementing agreed quality standards. Building relationships with other service providers. Increasing PPC education and training for service providers. Improving data collection from services to help meet the needs of clients and to assist in undertaking research into evidence-based models of care.

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Women's and Children's Hospital, South Australia	1989	<ul style="list-style-type: none"> PPC services provided from Adelaide to Northern Territory and Western New South Wales, including services to babies, children, young people and their families. Cases managed by paediatric CNC, who has responsibility for coordinating services on referral and supports individual palliative care teams. PCC care teams assigned to each family. Care planned collaboratively with regular case meetings, shared support and clinical expertise. Multidisciplinary collaboration. Paediatric CNC travels to regional areas to help establish the local service teams and provides advice about symptom management, pain relief and education. Follow-up undertaken by telephone and through telemedicine links. 	<ul style="list-style-type: none"> Service delivery through collaboration with local community-based services. PPC support teams tailored to meet individual family needs based on clinical best practice. PPC model provides effective home-based service to meet the needs of families. Increasing numbers of children with life-limiting illnesses able to die in their home environments. Close association of PPC services with the tertiary adult palliative care services. 	<p>Business plan available</p>	<ul style="list-style-type: none"> Obtaining resources to provide a bereavement support program. Obtaining additional funding to engage more staff, develop additional programs and support services, improve data-collection processes, establish legitimacy of the service and conduct clinical research. Increasing education, training and awareness in all health sectors. Communicating information about the level of available services, increasing understanding of palliative care and increasing referrals to the service.

TABLE 2.2: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002 (CONT)

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Port Augusta and Regional Palliative Care Service, South Australia	1993	<ul style="list-style-type: none"> • PPC services provided to the communities of Port Augusta including the rural areas of the Flinders and the far north regions of South Australia. • Holistic service delivery model addressing physical, psychosocial and spiritual needs with emphasis on a practical approach to the delivery of care. • Multidisciplinary, flexible, and client/family-focused service. • Children and their families have to travel to the Women's and Children's Hospital in Adelaide to undergo initial diagnosis and treatment and are referred back to local paediatricians following treatment. • Bereavement services are provided to families after the death of a child, including 12-month follow-up, and a two to four-year follow-up for siblings. • Early introduction of the palliative care team is to a large extent attributed to the paediatrician who has a high level of interest in this area. 	<ul style="list-style-type: none"> • Established network incorporating other service providers and the community. • Focuses on tailoring resources and services to meet the needs of clients. • Symptom and bereavement management services. 	<p>None available for PPC</p>	<ul style="list-style-type: none"> • Developing ongoing shared care partnerships with service providers, both in the region and at the tertiary referral centre. • Improving work practices to be outcomes focused, with an emphasis on improving continuity of care and service integration. • Building relationships with other service providers. • Undertaking specific staff development programs. • Increasing the profile of paediatric palliative care in the community.

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Oncology Department, the Canberra Hospital, Australian Capital Territory		<ul style="list-style-type: none"> Largely hospital centred and predominantly adult focused, but PCC is provided for children with malignant life-threatening conditions. Home-based support provided through PC program — service providers are not trained in PPC. Services available from social work, physiotherapy, occupational therapy and dietetics although under-resourced for demand. Bereavement counselling available but staff have limited experience in PPC. 	<ul style="list-style-type: none"> Services provided to PPC based on individual needs. Links with community-based services. Supportive link established between families and the hospital. 	<p>PPC strategic plan not available</p>	<ul style="list-style-type: none"> Providing appropriate training and development in the area of PPC. Improving networks with Sydney-based tertiary referral centres. Obtaining additional funding to support service operations in an integrated unit within the hospital. Improving communication regarding role of PPC within the hospital. Increasing the provision of complementary therapies. Improving access to appropriate respite settings, particularly for patients with non-malignant conditions.

TABLE 2.2: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002 (CONT)

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Launceston General Hospital Palliative Care Service, Tasmania	1997 2002 — PC physician	<ul style="list-style-type: none"> • Joint adult and paediatric service. • Operates as a consultancy model providing an individualised package of services to suit the needs of each client, with close linkages between service providers. • Referrals received from treating paediatricians, general practitioners, community nurses and disability services, and direct family referrals accepted. • Multidisciplinary teams. • Weekly multidisciplinary team meetings conducted by paediatric unit to discuss case management issues. • Client/family focused and structured with a high level of flexibility. • Formalised partnerships with service providers and clients across acute and community services sectors. • Regional multilayered model with general practitioner managing primary care with a range of other service providers, including the PC service. 	<ul style="list-style-type: none"> • Unit of care encompasses both the child and the family. • Establishment of working partnerships with service providers enables care to be coordinated and limited resources to be used more effectively. 	<p>PPC is incorporated into palliative care strategic plan</p>	<ul style="list-style-type: none"> • Increasing the availability of PPC consulting services to deal with future increases in demand in both the acute and community health sectors. • Improving continuity of care and service integration. • Focusing on building partnerships with service providers across the continuum of care.

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Princess Margaret Hospital, Western Australia	1984	<ul style="list-style-type: none"> • Case management and brokerage model. • Psychosocial coordinator for each patient. • Decisions and course of care driven by patient and family. • Liaison nurse provides support to community nurses providing in home care. • Outreach service. • Inpatient respite and pain control. • Home assessment and advice regarding required changes by occupational therapist. • Focus on working with both the patient and siblings. • Links with community nursing and general practitioners. • Consultation liaison service provided by psychiatry department to PPC clients. • Focus on ensuring that a smooth transition occurs between palliative and bereavement components of care by linking families to support groups. 	<ul style="list-style-type: none"> • Flexibility to provide services in hospital or in the home. • Case management model enhances arrangement and delivery of services. • Links with community-based services and mix of case management/brokerage. • Home-based nursing services are provided through Silver Chain, a Western Australian charitable organisation. • Silver Chain also provides access to a pool of general practitioners across Perth with interests and experience in palliative care. • Camp for siblings and links with Canteen. • A strong, supportive link between families and the hospital. 	<ul style="list-style-type: none"> • Developing the service and focusing on gaining acknowledgment of PPC as a clinical entity. • Obtaining additional funding to support service operations as an integrated unit within the hospital. • Improving arrangements for pain management. • Improving communication about the role of PPC within the hospital. • Improving access to appropriate respite settings, particularly for patients with non-malignant conditions. 	

TABLE 2.2: SUMMARY OF CASE STUDY MODELS OF PAEDIATRIC PALLIATIVE CARE BY SITE, 2001–2002 (CONT)

Case study sites	Established	Model features	Effective elements	Current service plan	Future directions
Peel Community Palliative Care Service, Western Australia	2001	<ul style="list-style-type: none"> • Adult and paediatric PC service. • No medical staff employed, though a medical officer was about to be appointed for three sessions a week. • Palliative care services in the home. • Initial focus on developing a relationship with the identified clients and their families before seeking to initiate physical assessment and palliative care. • Close liaison with general practitioners and treating medical teams. • Nurse located with the local general practitioner acts as a resource person and helps to ensure early referral to palliative care. • Significant network of volunteers provides support to carers (adults and children). 	<ul style="list-style-type: none"> • Support and involvement of local general practitioners. • Support available for patients and their families. • Effective link to a network of volunteers, and attempts to match volunteers to patients and carers. • Maintenance of effective links with treating medical teams in metropolitan area. • Holistic approach to the provision of care. 	<p>PC plan available</p>	<ul style="list-style-type: none"> • Given the low demand for paediatric palliative care services, there were no specific initiatives identified with respect to future directions.

Variations in service delivery

As can be seen from the information presented in table 22 above, there are significant variations in the models of care provided across Australia. Our review of the literature and case study findings has shown that there is no one model of service delivery that can respond to the problems facing health care professionals responsible for providing paediatric palliative care to families. There are several reasons for this.

Variability in the demand for paediatric palliative care services

Our findings have shown that the more comprehensive models of care have emerged as a result of providing services on either a statewide basis or where there is a significant demand at the local level (for example, from specialist paediatric hospitals). Where the demand for paediatric palliative care services is low, there is a tendency for service providers to incorporate those services into the overarching palliative care program, which is predominantly for adults.

Variability in the complexity and prognosis of conditions

One of the principal reasons for this proliferation of different models is significant variability in the complexity and prognosis of life-threatening conditions, ranging from short acute illnesses to the more prolonged conditions that are often associated with disabilities and require complex medical care over a long period of time. Under these circumstances, the philosophy of care is to provide responsive physical, emotional, social and spiritual support in accordance with the needs of children and families at any given time in the illness trajectory.

Differing family choices

From our research findings, it is clear that paediatric palliative care services must be family centred to empower families to make informed choices about the level of care to be provided during the palliative episode. Our consultations with service providers have shown that, for the most part, families prefer their children to die at home in an environment in which the children feel safe. This requires a comprehensive and holistic model of care capable of providing a myriad of home-based paediatric palliative care services. Close collaboration between hospital-based and community-based primary palliative care teams is necessary to enable families to continue to care for their children in the home environment.

However, some families may not have the physical and emotional resources to deal with caring for their children at home and may opt to place them in a hospital or children's hospital at the end of life. In these instances, it is important to ensure that appropriate facilities exist to accommodate the needs of these families in order to make the experience more comfortable.

Range of service providers

An examination of the case study findings has also shown that paediatric palliative care services can be provided by a range of service providers. Inpatient care is provided in a variety of settings, including specialist children's hospitals, general hospitals or designated children's hospice facilities. Similarly, home care can be provided in a variety of ways, such as community-based or hospital-based care, or a combination of home-based care coordinated by hospital and community staff. In addition, respite care for parents and siblings and, in some cases, comprehensive bereavement programs are available for the whole family. Each of these service providers is, for the most part, bound by its own internal service delivery protocols.

Variations in level of services offered

Our review has also identified a significant difference in the availability of paediatric palliative care services offered to families, which is largely determined by the availability of resources and the demand for these services. Our case study findings demonstrated that social support services for children and families are lacking, including respite and bereavement support programs, and emotional, spiritual and sibling support programs. Similarly, there is a lack of psychosocial and bereavement support for health care professionals who are charged with providing paediatric palliative care services. Once again, insufficient resources were identified as the primary reason for these differences.

Availability of trained paediatric palliative care staff

The issue of education in the area of paediatric palliative care was raised by stakeholders on numerous occasions. There were very few service providers who had tertiary training with, or containing, a paediatric palliative care focus. We understand that there is only one paediatric palliative care post-basic program available for nurses in Australia, conducted by Flinders University in South Australia. We were also advised that there are limited educational opportunities in the area of paediatric palliative care.

To compensate for this lack of training, a number of states have implemented training programs, both general and child specific, to increase the skills of other professionals who may not come into contact with children in palliation on a regular basis. Additional funding is required to provide paediatric palliative care training and education, particularly for staff in community-based agencies, as this area is now seen as developing into a specialty, to meet the growing demand.

Gaps in service delivery

The following is a summary of the areas where there were gaps in the service delivery model.

- 1 **Late referrals** Many stakeholders indicated that referrals to paediatric palliative care were not received until the active treatment had been withdrawn, the child's condition had rapidly deteriorated and the family was often in a highly charged emotional state. We were advised that one of the greatest barriers to providing quality paediatric palliative care was mistrust and ignorance about the role of paediatric palliative care and about the overarching goal of achieving the best quality of life for patients and families. In these instances, the care of the child was often compromised, which led to territorial medico-politics and resulted in the family not being offered, or not being made aware of, the full range of paediatric palliative care services in time.

Late referrals to the paediatric palliative care service can produce a number of negative outcomes including:

- children in their terminal phase enduring significant suffering because of inadequate recognition and treatment of symptoms;
- aggressive treatment modalities being used to effect a cure; and
- significant trauma being experienced by parents, siblings and the extended family at the death of a child, which has the potential to complicate grief reactions and impair long-term adjustment.

- 2 **Inadequate funding** We were advised that the level of funding available for paediatric palliative care was insufficient to meet the increasing demands for paediatric palliative care services and the needs of children with life-threatening conditions and their families. There were also insufficient resources allocated to meet the high cost of the pharmaceuticals required for pain management. The cost of pharmaceuticals was a significant financial burden to many families. Where possible, these medications were provided through other health care programs (for example, a hospital in-the-home program).
- 3 **Insufficient access to respite services** We were advised that paediatric palliative care service providers were unable to meet the demand for respite services because of limited funding. We found that limited out-of-home respite services were provided. However, these services were used for children with chronic conditions rather than for short-term respite for families.
- 4 **Access to transport** Access to adequate transport necessary to move the client and the required equipment between the home and facilities was problematic for some families. There were no government schemes to support client transportation.
- 5 **Cultural differences** We were also advised that, in cases where the child had a non-English-speaking background, local support agencies experienced difficulties in taking responsibility for case management because of the inherent complexities of cultural diversity. This has highlighted the need for additional resources to facilitate the development of culturally sensitive support services.
- 6 **Service access in rural areas** Families living in rural and remote areas did not have the same access to services as those living in regional and metropolitan areas. For these families, regular telecommunication links with service providers were the main method of receiving support. Community support services in rural and remote family need further development.
- 7 **Lack of information to help in improving service delivery** Because of the limited availability of clinical and outcomes information, there were limited opportunities for best practice benchmarking. In addition, there was little evidence of clinical and non-clinical indicators associated with the delivery of paediatric palliative care services.

Barriers to effective service delivery

The findings of our case study review show that there are a number of barriers to providing effective paediatric palliative care services.

Focus on curative care

One of the most prominent barriers identified related to a culture of denial that children do die from life-threatening conditions. When treating practitioners and families are first confronted with a life-threatening diagnosis for a child, they are reluctant to accept that the child will die and want to try everything possible to save the child. Many informants suggested that there was a significant focus on the curative model of care, which resulted in difficulties in gaining access to clients requiring palliation because they were pursuing curative treatments. We were advised that, in many instances, clients are not aware of all the treatment options available and often were not offered palliative care support until the end stage.

In addition, the tendency to pursue the curative and life-prolonging treatment of children has also resulted in a failure to fully appreciate the suffering that these interventions can cause. Informants

advised that there were many cases where potential sources of distress were not adequately considered, and opportunities to prevent or relieve distress were missed through the late referral of children to palliative care services.

Barriers affecting care coordination

A range of diverse issues affecting the coordination of care was highlighted as part of our case study review process.

- 1 **Lack of resources** Some informants advised that they experienced difficulty involving community service providers because of a lack of resources and funding, as the primary focus was on ensuring appropriate support services were provided to families and their children.
- 2 **Delayed referrals** Timing of referrals to palliative care services is critical to ensure a smooth transition from the curative to palliative phases of care. There were many instances cited in which referrals were made to the service too late to enable the full benefit to be realised by families.
- 3 **Focus on curative interventions** Some members of the medical profession and families did not trust in palliative care service providers. In part, this was attributed to some medical professionals or the family members not wishing to give up on curative interventions.
- 4 **Spatial geography** Geographic distances can cause difficulties with organising care and transport for children and necessary equipment.
- 5 **Lack of clinical and administrative protocols** Our case study review found that, aside from those of a number of specialist paediatric palliative care agencies, no clinical and administrative protocols had been developed for providing paediatric palliative care that focused on integrating and coordinating the service. Service providers often cite problems experienced with coordinating the care needs of children and their families, particularly those of children who had complex chronic problems that required treatment by hospital, home and community-based services. These services are provided by a range of professions and agencies working in separate geographic, organisational and even cultural areas, who are bound by their own procedures. Those involved in caring for children with life-threatening conditions should collaborate in establishing procedures that support coordination, continuity and the timely transmission of information through and between care providers.

Barriers to providing services to clients from culturally and linguistically diverse backgrounds

The following is a summary of issues identified by stakeholders with respect to paediatric palliative care services for families from culturally and linguistically diverse backgrounds (this includes families from Aboriginal and other non-English-speaking backgrounds).

- 1 **Lack of input from cultural communities** Specific input is required from cultural representatives in the case management of patients from non-English-speaking backgrounds, which has been difficult on occasions. In particular, Aboriginal groups can be difficult to tap.
- 2 **Limited access to interpreters** Currently, additional access to interpreters is required to improve the understanding of different cultural norms and needs, and to improve cultural communication and the use of correct terminologies (language) with clients and their families.

- 3 **Lack of understanding of family dynamics and structures** Further research is required to develop a more comprehensive understanding of the family dynamics and the structures involved in different cultures, throughout the care and support process.
- 4 **Lack of resources** Considerable resources (time and funds) are required to establish a relationship with different communities and to gain their trust. Written materials have to be translated, media have to be specifically targeted and interpreters funded.
- 5 **Relatively small numbers of children** The number of children from culturally or linguistically diverse backgrounds requiring paediatric palliative care is very small, which complicates decisions about equity of access relative to the totality of needs in this area.
- 6 **Lack of trained multicultural staff** Currently, there is a lack of suitably trained multicultural staff to support the services provided to families from culturally and linguistically diverse backgrounds.

Barriers to general practitioners

General practitioners (GPs) have an important role in providing care to children and their families, particularly where there is a long-standing doctor–family relationship. Our review findings have shown that GPs are unlikely to see many children with life-limiting conditions, as most of the medical care required is provided by specialists in the acute care sector. We were advised that some paediatricians required GPs to have a greater involvement at the point when all curative options were thought to have been exhausted, as they felt that specialist paediatric involvement was not necessary then. Views were canvassed on the role of GPs in providing primary care and, more specifically, palliative care services for children and families. The following key issues were identified.

- 1 **Lack of communication** We were advised that there was, in the main, little information sharing and communication between GPs and those in the acute care sector. Often, the GP became involved only when the patient was close to the end of life. This made the situation very difficult for both the family and the GP.

The role of the GP is often distanced from the family because the family establishes a very strong link with the treating paediatrician. In these instances, a request for GP involvement typically occurs much later, once the decision to discontinue curative treatment has been made and the child requires home-based care and medical supervision. It was also noted that, in rural areas, GPs were more likely to have a closer involvement and often performed the role of case manager. General practitioners required more timely communication from hospital-based services regarding the condition of the child at the point of diagnosis. They also required information after the child's discharge about the child's condition, future treatment plans, and what the child and family had been told and understood.

- 2 **Lack of support network** Some GPs may not encounter clients requiring palliative care very often, if at all. We were advised that it can be frightening for GPs to become involved in paediatric palliative care and that they may not be familiar with the services and options available to the family. Some of the ways in which GPs may obtain education in paediatric palliative care are learning by experience, using educational resources, asking questions, and attending conferences at tertiary institutions. In this context, the suggestion was made that GPs needed access to adequate information and to a specialist services support network.
- 3 **Exclusion of GPs from the care process** General practitioners indicated that they should be actively involved in the care of the patient and have open communication with the treating specialist. It was seen as important that service providers in the acute health care sector also made sure that GPs were

included in the whole process. General practitioners are often only seen as prescription writers when ideally they should be seen as part of the continuum of care. They can be distanced during some care phases, but should be involved when the patient is in a home-based situation.

Barriers to providing volunteer support services

While using volunteer services was considered an important part of providing a comprehensive paediatric palliative care service, a number of barriers were identified.

- 1 **Difficulty in recruiting volunteers** We were advised that there is some difficulty in recruiting and training volunteers in rural and remote regions. Some agencies had developed specific strategies for expanding their volunteer training program, for example, Very Special Kids had implemented a comprehensive online community approach.
- 2 **Some families preferred not to use voluntary services** Some informants advised that some families feel guilty using a voluntary service and would prefer to use a nurse. Families usually have their own support network when the patient is a young child and a volunteer service is generally only used where the child has a longer term illness.
- 3 **Lack of training to provide required level of in-home support** We were advised that there were instances where volunteers were unable to provide the required level of in-home support as some experienced difficulty in delineating personal boundaries and inadvertently became too emotionally involved with the family. This means all new volunteers must be carefully screened and trained in order to identify those who may not be suited to this challenging environment.

Evidence-based best practice

The literature about best practice models of paediatric palliative care advocates using integrated models of care that include developing and implementing formal clinical and administrative protocols to define the expectations of, and responsibilities for, the quality of care provided by health professions and agencies with respect to procedures for palliative, end-of-life and bereavement care for children and families. These protocols should also promote the coordination of continuing care and the timely provision of information to caregivers, health agencies, schools and families. Our case study review sought to evaluate the extent to which the existing paediatric palliative care models were consistent with evidence-based best practice and to identify key areas for improvement.

Opportunities for improvement

Our case study review findings highlighted a number of opportunities for improving the delivery of paediatric palliative care services.

- 1 **Greater integration of paediatric palliative care services** Many informants considered that a paediatric palliative care program can best meet the needs of children and families by integrating all aspects of care within unified goals and offering interdisciplinary, holistic services. Then, the range of services could permeate the health care system to ensure the delivery of a comprehensive paediatric care service with a focus on total client management. It would also provide families with a range of choices from which they could make informed decisions about the future care of their child. These models of care would require a shift from the current demarcation between curative and palliative care to a system that can make the continuum of care seamless. This view is also supported by our literature review findings and is in line with the development of innovative models of care in the UK and the USA.

- 2 **Knowledge sharing** Establishing a network of key people across the state or territory to share knowledge of best practices in this field and provide an additional support infrastructure for all health professionals was considered important.
- 3 **Increased education and awareness of the role of paediatric palliative care** Increasing the knowledge base of paediatric specialists to provide for a more comprehensive understanding of, and more working experience in, paediatric palliative care and support services was also considered important. Developing strategies to improve awareness and educational opportunities in the community and the medical profession about the role of paediatric palliative care would help to obtain earlier referrals and to improve understanding and communication. Informants also suggested that a redefinition of paediatric palliative care is required so that the current stigma of association with death and dying is no longer the focal point and it is replaced by an emphasis on support and quality of life issues.
- 4 **Development of protocols for bereavement support** As previously stated, a comprehensive bereavement program is required for families who have lost a child to a life-threatening condition. In this regard, a common set of national protocols should be developed to enable:
 - the identification and coordination of culturally sensitive bereavement support services for parents and siblings;
 - the definition of bereavement support roles for hospital and community-based staff involved in providing paediatric palliative care services; and
 - the provision of appropriate debriefing programs in response to the bereavement needs of, and the stresses faced by, professionals involved in assisting dying children and their families.
- 5 **Development of information programs** National and state-based information programs and associated resources should be developed to assist clinicians and families in local and rural communities, and should include the following:
 - consultative services to advise GPs and local community service providers on all aspects of care for children and their families, from diagnosis through to bereavement;
 - clinical guidelines and information that will assist families to advocate for appropriate care for their children; and
 - professional education programs to support palliative, end-of-life and bereavement care for all families requiring these services.
- 6 **Review of the appropriateness of funding** In order to address the service improvement issues that have been identified, the appropriateness of the existing funding mechanisms and levels must be examined with a view to providing a designated resource allocation for paediatric palliative care services. Standards for providing and funding paediatric palliative care services have to be further developed and integrated into the health care system as a whole. Additional funding could be used to address a number of service gaps, including to develop specific research programs and better bereavement and education programs.
- 7 **Education of health professionals** The case study reviews have highlighted the need for appropriate educational programs for all health professionals about palliative, end-of-life and bereavement care. While we acknowledge that providing education programs alone would not guarantee changes in attitudes or behaviours, such programs would provide the essential basis of knowledge, skills and

ethical understanding for all service providers involved in providing paediatric palliative care. These changes to the existing generalist, paediatric and specialist education curricula would contribute to the increasing acceptance of paediatric palliative care as a defined and accepted area of teaching, research and patient care expertise.

Currently, there are only three paediatric palliative care specialists in Australia. This number should be increased to ensure sustained support for service improvement. Informants also suggested that continuing education and paediatric palliative care fellowships or similar training opportunities be offered. Additional resources would be required to implement training programs in schools of medicine, nursing and social work, including developing minimum standards for program content and competency-based testing.

8 **Need for ongoing research** Many informants stressed the importance of undertaking research to inform the development of best practice models for paediatric palliative care, in addition to other research initiatives. Currently, research into paediatric palliative care is limited and systematic data to support research activities are not readily available. Informants expressed the view that specific funding should be provided for approved research projects in the areas of paediatric palliative, end-of-life and bereavement care that would be innovative, would build on existing evidence, would fill gaps in knowledge and applied practice, and would incorporate care from the time of diagnosis through to bereavement. The identified research priority areas included:

- clinical interventions such as symptom management;
- early identification of children who would benefit from palliative care;
- methods for improving decision making and communication;
- the development of tools to assess the quality of, and satisfaction with, paediatric palliative care services;
- methods for improving the education of health professionals, other service providers and families;
- innovative models of care for delivering, coordinating and evaluating care that include interdisciplinary care teams and quality improvement strategies; and
- models of bereavement and sibling care.

Chapter 6

Consumer needs analysis



This chapter presents a summary of the results of the qualitative research derived from the 19 in-depth interviews with families who had used paediatric palliative care services in New South Wales, Victoria and South Australia.

Profile of selected consumer participants

Qualitative research does not claim ‘representativeness’ in the statistical sense, but it is important in a broad survey such as this to sample a wide range of experiences. The 20 families interviewed had eight children who died from ‘non-oncological’ disorders and 12 who died as a result of some type of childhood cancer. The one interview that could not be used related to a child with cancer, and the interview could not be used because a recording problem rendered the tape untranscribable. Fourteen of the children who died were boys and six were girls. Of those children who died, the youngest was nine months old and the oldest was 19 years.

Participants’ experiences of diagnosis

When so much of the current discourse surrounding health care is couched in the oblique language of ‘best practice’, ‘seamless webs of care’, ‘evidence-based benchmarked services’, ‘consumer-focused mission-critical strategic planning’ and the like, families may wonder what is actually being discussed.

At the outset, it is therefore appropriate to focus clearly on what is at the heart of this component of the review and that is death, pain and loss. This is about those who live with the knowledge that the most precious person in their world — their child — has been taken from them and that this loss has occurred sooner than should ever have been the case. This is about a depth of anguish, loss and grief that seems beyond the grasp of those who have never found themselves in this situation.

However, it is also about positive possibilities for, even in the midst of suffering and the inevitability of an untimely death, there are small seeds of hope to be nurtured: hope for comfort, for freedom from pain, for giving and receiving care, for precious and enjoyable times spent together, for creating and sustaining valued memories that will far outlast physical death, and for what is oddly but rightly called ‘a good death’.

This chapter will explore a range of parents’ and family members’ experiences and perceptions of palliative care service. The phrase ‘paediatric palliative care’ is itself something of a ‘dressing-gown’ phrase designed to cover over the stark reality of a child’s dying. If this study of consumer perspectives is true to its purpose, it will allow the voices of the participants who have experienced the death of a child to be heard clearly. This will enable us to understand something of how the rhetoric of services currently translates into the reality of experience for the parents, their children and their families.

More importantly perhaps, it should spur policy makers and service providers to create a palliative care framework and service for children and young people which is grounded in a deeper awareness and understanding of their lives and expressed needs. There could be no better way of demonstrating our appreciation to the parents and other family members who have helped so generously with this study.

Diagnosing a life-threatening condition

Almost all participants interviewed began their accounts by describing how they first became aware that 'something wasn't right' with their child. As they explained how this general unease and concern moved on to greater anxiety, they told an almost archetypal story of asking for advice, visiting local doctors or hospitals, being told that there was 'nothing to worry about' and eventually being referred to a specialist service or for more sophisticated testing that eventually confirmed the presence of a life-threatening condition.

These accounts of diagnosis almost form a discrete case study in themselves, as the various experiences illustrate important aspects of each of the major themes that this consumer interview survey sought to explore. The interviewees described services that were sensitive and helpful and others that seemed incapable of listening and responding. They encountered health professionals who tried to inform with honesty and compassion and others whose evasiveness and insensitivity almost defy understanding.

Initial parental concerns

For many of the participants, the early indications that something was wrong with their child were no more than what might be called the 'normal' maladies of childhood, such as loss of appetite, complaints of vague pains, tiredness, a swelling, a raised temperature or a change in behaviour. Typically, they would 'wait and see' if these problems resolved or would take the child to their general practitioner or child health clinic. However, when these signs or symptoms failed to resolve themselves or improve, a sense developed that something more serious may be wrong.

Persistence of symptoms

Participants' concerns grew as these minor signs or symptoms persisted or worsened and they sought further medical advice. They described this as a trying time as they often found it difficult to either obtain a referral to a specialist or to have professionals take their concerns seriously. It seemed that parents and carers needed a degree of tenacity and persistence if their concerns about their child were to be taken seriously. They may not have recognised it at this time, but the participants were beginning to learn of the phenomenon of 'fighting for services' that is so familiar to more 'experienced' parents of children with a serious illness or disability.

Being persistent in such a context can be difficult for parents as they run the risk of being perceived and labelled as difficult or neurotic. It is also difficult for parents or family members to challenge in any way the knowledge and expertise of health care professionals and specialist services. While the idea that parents are experts regarding their children is generally accepted in principle, in practice, parents seem to be given a different message — 'What can you really know? You are just a mother/father.'

Communicating the life-threatening diagnosis

After the children had undergone further tests and examinations, the serious nature of their illness or condition was usually identified and this information was conveyed to their parents or carers. This area of diagnosis and communication with family members has rightly received considerable attention in the

health care literature (see, for example, Blasco, Kohen and Shapland 1999; Greenberg et al 1999; Bartel et al 2000; Masri et al 2000; Farrell, Ryan and Langrick 2001) as it is recognised that this may be one of the most traumatic and distressing events that a family can experience. For this reason, many medical and nursing education programs have focused on how best to convey bad news and very serious diagnoses to both children and their parents or carers. It is a concern that the experiences of the participants in this study show that this aspect of diagnosis continues to be problematic.

Participants described a range of experiences of learning or being told of their child's life-threatening condition. Few were told honestly and sensitively, some picked up on coded signals, others felt that they were drip-fed small pieces of information only; some were critical of the timing of the disclosure and, for some, the insensitive manner in which they were told still causes them great anger, even some years later.

There is a paradox in participants' accounts of their experiences in that they desperately wanted information about what was 'wrong' with their children and about what was possible or was happening with treatment options. However, they also described the part of them that 'didn't want to know' and how there were times when they would purposely not ask particular questions because they did not want to hear the answer that they feared. This idea will be discussed in more detail in the section called Finding information below, but here this paradox illustrates that diagnosis and giving parents or carers bad news is not simply about imparting factual information. It is also about establishing the kind of trusting, compassionate and empathic relationship between parent or carer and professional which will empower and sustain the family through the difficult period of investigation and treatment that is likely to follow the diagnosis.

Participants often suspected that their children's conditions were serious before any definite diagnosis had been offered. They described this intuitive sense as 'just knowing' that something was wrong. They also picked up on the subtle changes in demeanour, the non-verbal signals and the coded hospital practices that told them that something was seriously wrong with their child. Participants appreciated professionals who were honest and open with them, but a crucial caveat here is that honesty and frankness are not synonymous with bluntness and insensitivity.

Such honesty and openness recognises that diagnosis and imparting bad news is not solely about giving information, but about the quality of humanity shared by parents or carers and professionals. The information is undoubtedly important but, as so many participants attest, information per se means little without the empathic and respectful discussion of what it actually means to this family's life and the life of the child. Participants therefore appreciated openness and honesty from the professional who was sharing and imparting information. They also valued professionals who worked with them and with their child in a caring alliance.

Participants reported many different 'timings' of diagnosis, as would be expected given the wide range of the children's conditions. Some participants received a definite diagnosis relatively quickly following tests and investigations, whereas others waited months or even years before a definite diagnosis was reached. The interviewees seemed to accept that diagnoses often involved sophisticated and repeated testing, but were concerned when diagnostic services seemed slow to respond to what they saw as the urgency of the child's condition.

Reacting to the diagnosis

Other participants 'heard' the diagnosis offered but did not fully comprehend the implications of some of the medical terminology used. A striking example here was the parent whose child had just been diagnosed with a 'metabolic' disorder. From a parent's perspective, 'metabolic disorder' makes sense as

there is nothing in the term to suggest its often degenerative and fatal outcome. A similar situation arose in a previous study (Darbyshire, Haller and Flemings 1997) of parents' palliative care experiences, when a parent misunderstood the diagnosis of 'progressive' neurological disorder. In everyday non-medical language, the term 'progressive' has connotations of improvement, of moving forward, of getting better, yet the medical sense of 'progressive' points instead to a relentless decline in function and health.

When participants were asked at interview if they could suggest improvements to paediatric palliative care services, very few suggestions were explicitly directed at the diagnostic phase. However, some suggested that professionals be asked to use fairly obvious helping strategies, such as speaking to the parents or family members again and checking what had been 'heard' and understood and what would have to be presented and explained again.

Finding information

A specific objective of the consumer interviews was to obtain a record of participants' experiences of finding useful information about both their child's condition and all aspects of their treatment and care, including the period of palliation. Information is clearly a very broad area and, not surprisingly, participants described a wide range of perceptions here, from great satisfaction to marked frustration.

The nature of information sought and required was similarly broad. Participants needed clinical information about the child's illness or condition in a form and at a level that they could understand and which did not 'baffle them with science'. They also needed practical information about the implications of the child's illness. In everyday terms, information was required to answer questions such as:

- what does this illness mean for the child and family and their everyday lives?;
- what will they be able to do or unable to do?;
- what special equipment, facilities, medications or other treatments will be needed and where will these come from?;
- what are the financial implications of the child's care?;
- what help is available for the family?;
- who should they contact about this?;
- who will be with them at this time and how will they help?;
- what about the child's schooling and social life?; and
- what kinds of activities will the child be able to participate in and to what extent?

The last and most difficult questions for parents to approach were those about the last stages of life and eventual death such as:

- what will this be like?;
- how will they know that death is imminent?;
- how will they recognise it when it happens?; and
- what should they do then?

This is an extensive list, and yet there are many more questions that these families faced which they required skilled, knowledgeable assistance to answer.

Availability and value of information

Participants had very different approaches to their needs for information and their desires to access and use this. Some described how they would leave no stone unturned in their search for information, using libraries, friends and contacts and, of course, the internet.

Information, however, is not simply neutral, factual data. Information has meaning for parents and family members and this helps to explain why several participants described purposefully ‘avoiding’ or ignoring some available information for various reasons. There was a sense shared by some participants that even acknowledging their need for specific information meant that their child was thus affected. They described how they would choose not to ask particular questions or request particular information for fear of receiving the kinds of answers that they had been dreading.

It is rather too glib to dismiss or psychopathologise this parental thinking as being simply ‘denial’, for such thinking is closely bound up with other complex thoughts and emotions which draw hope, loyalty, courage and the very core of parenthood and caring into the equation. For example, some participants expressed the sense that, if they acknowledged the inevitability of the child’s premature death by requesting related information or asking specifically about palliative care, it was akin to giving up hope, or worse, giving up on their child.

Participants described some services where information was readily available, usually in the form of books, leaflets, videos and so on. These were often valuable, as parents or family members could choose to read or watch as much or as little as they wanted. As mentioned previously, the internet has also revolutionised the world of medical information and information which once would have been essentially restricted to health professionals is now freely available online. In addition, parents can now communicate with others across the world, for example, via the web page of a support group for parents whose children have extremely rare syndromes or conditions. The advantage for families is obvious — there may only be one or two other families in Australia with a child in a similar situation, but hundreds in the online world.

Where participants felt that the existing information was less satisfactory was in its failure to focus on death itself and the period immediately leading up to this point. It is worth noting at this point that participants had similar comments to make about ‘shying away’ from death even about some palliative care services.

Another parent, whose child had been in a Children’s Hospice, articulated very clearly the sense shared by many participants that a point was reached when detailed, specific and potentially painful information and knowledge about death in general and the child’s forthcoming death were required.

Information and knowledge about service

This was a more contentious aspect of information finding. Participants recounted many more difficulties and frustrations with trying to find out about facilities and services than they did with trying to obtain booklets or videos. Part of the difficulty that these participants faced was, of course, that they had never been in that situation before and were very much strangers in a strange land. Not only did they have to negotiate their way through the layers of health, social, educational and community services and associated offices and departments, but they had to do this in the knowledge that their child was very seriously ill or dying.

As many participants explained, it is very difficult to ask for information and advice about services if you know neither what is available nor what you actually need. Even those with ‘insider knowledge’ of the health care system found it difficult to discover what services were available to help a child and family following the diagnosis of a serious illness or disorder.

Making information useful and accessible

One of the experiences that participants described most positively was working closely with health professionals or other ‘supportive friends’ who helped them navigate through this strange new world of clinics, hospitals, treatments and all of the other paraphernalia of serious childhood illness and paediatric palliative care. In addition, such a guide often gave valuable help to parents and families as they made their own difficult personal journeys through their feelings and emotions. Other families obtained similar help in accessing and understanding information from support groups, voluntary organisations and other such associations.

Participants’ suggestions about how information access, availability and use might be improved centred not on the amount of information that should be available but on how information was presented. Here, the medium was indeed the message. They wanted:

- to be offered information without having to ask constantly;
- to be able to ask without being made to ‘feel stupid’;
- explanations that they could understand, question and clarify;
- the ‘grounding’ of a caring relationship with a central health professional who was closely involved in their child’s care and who had skills and knowledge required for both paediatric and palliative care; and
- the support that was so often necessary when information was being sought or provided.

Participants’ experiences of using services

This section outlines the range of participants’ experiences of using palliative care services.

Obtaining services

Some participants described how services had to be ‘fought for’ or ‘grovelled for’. They described the frustrations of trying to find out what their children needed, what was available and how they could access or obtain these services. This usually involved rounds of telephone calls or writing letters to various agencies and people within these agencies. Often, it seemed that the simplest of services was the hardest to obtain.

While all of these families were linked through the common bond of having experienced the death of their child, their need for support and services was as distinctive as the individual parents, families and children concerned.

Positive experiences of services

Participants described their encounters with many valuable services and ‘excellent’ people who were instrumental in helping them and their children through the many trying times of life-threatening illness, palliative care and eventual death. The people who were most appreciated did not belong to any

single group or discipline. Doctors, nurses, allied health professionals, music therapists, volunteers, parents of other dying children and more were all cited as being guides and supporters, many of whom now have a place in the hearts and memories of the interviewees and their families.

They found it valuable to talk to other parents or carers who had lost a child and who had 'been there'. They appreciated those people who listened to them and who valued their knowledge and expertise concerning their own child. They wanted flexibility in service provision and appreciated services and people who were capable of adapting and continuing to support them even when their views, plans or moods changed.

- 1 **Accessibility and availability** Children with a life-threatening condition have needs which are both complex and do not keep office hours. Parents and carers therefore described very positive experiences where services and people had been clearly available and 'there for them', if and when they were required. These were often as simple as their having a known and trusted person's contact number that they could use, if necessary, at any time of day or night.
- 2 **Knowledge, skill and action** Although the 'people' of the service providers were extremely important, so was their actual ability to be of tangible help and to 'make things happen'. In participants' eyes, 'support' can become rather an empty cliché if it is not translated into genuine physical, practical, emotional and social help. Participants encountered many service providers whose proactive and 'can do' attitudes to potential 'problems' was a significant help. This not only solved the immediate problem, but also generally helped participants' morale by countering the pessimistic and paralysing sense that 'nothing can be done'.
- 3 **Friendliness, warmth and humanity** When participants discussed the services that they had valued, they repeatedly remembered the people who engaged them and their children not with cool professional detachment, but with warmth, humanity and friendliness. This is a skilled, subtle approach that does not lapse into presumptuous overfamiliarity or inappropriate, 'over the top' cheerfulness. Participants found it difficult, if not impossible, to work in any kind of meaningful partnership with service providers who were incapable of such a friendly, human approach and they would regularly describe how they would avoid or 'bypass' such people wherever possible.

The service providers who could work in this way became family friends in a very important sense for participants. The use of the word 'friend' is always problematic in this context, as it may suggest, for example, that all nurses and parents must become best friends in the name of providing a good service. This is clearly neither a desirable nor a realistic proposition and so it is perhaps more useful to think of this relationship as being one grounded in professional friendliness. The service provider does not become part of the family but, as one parent suggested, part of an 'extended family of care' that has surrounded and supported the child and family.

These relationships are based on collegiality and mutuality and are born out of a shared experience of caring for, and eventually bearing witness to, the death of a child. A kind of bond is certainly forged between parents, other family members and those who have helped care for the child, especially during the 'tough times' of treatment regimes, pain and distress, and the child's death.

- 4 **Respect for the children and their choices** Participants generally had very positive recollections of staff and other personnel who not only treated them with care and respect but who extended this respect to their children. It may seem a self-evident statement that children are important people in their own right and are thus deserving of consideration and respectful treatment. However, participants' accounts of their unsatisfactory dealings with health care staff suggested that children continue to be overlooked, patronised and otherwise ignored by professionals. Parents of babies

and younger children remembered the professionals who had recognised and responded to their child as a unique and special person rather than as a 'case' or 'disease'.

Negative experiences of services

In addition to being asked about helpful and valuable people and services, participants were also asked about the times when their encounters with services and staff had not been positive. They tended to respond here by describing shortcomings in service provision at a general level. However, when they described their negative experiences with staff, their memories were almost always of particular incidents involving particular people. Their memories of these encounters were often still raw and fresh and their anger at the situation was still apparent even years after the event.

- 1 **Service unavailability, inaccessibility and inefficacy** Participants' dissatisfaction with services related predominantly to the services' perceived unavailability, inaccessibility and inefficacy. An obvious difficulty facing the participants at this time is that their world had been upended and they were now in a completely unfamiliar situation, particularly regarding their children's current and future needs. This means that it was very difficult, if not impossible, for them to anticipate what they needed then and in the future, and ask for this.

Participants found multiple referrals and uncoordinated services to be especially frustrating. This was usually described as playing 'telephone tag' with numerous agencies, departments and people and, at the end of the day, often failing to find the right person or the person who could make a clear decision.

Most participants described their hospitalisation experiences positively, but when they experienced lapses in what they considered to be 'basic care', they felt not only unhappy about the particular incident but also apprehensive about leaving their children unattended in the future. In short, their confidence in the ward, unit or hospital had been shaken.

- 2 **Distressing encounters with professionals** Much more prominent in the participants' accounts were their recollections of specific times when staff and professionals had behaved or reacted in ways they interpreted as showing disregard, disdain or disrespect towards either them or their children. They also described these encounters as interactions with professionals who seemed not to care about them or their children. This is not a new phenomenon in health care, as much literature has described 'clients'/patients' experiences' within the health care system.

Similarly, from the professionals' perspective, there is no shortage of material describing ways of enhancing communication skills, staff attitudes and even 'customer service' approaches. Yet it seems from these participants' accounts that those who are facing the serious illness and loss of a child can still experience interactions with professionals which leave them feeling not simply 'unsatisfied customers', but extremely angry, wounded and even unwilling to return to a particular service.

Several themes ran through the participants' descriptions of their negative experiences with professionals. Many described episodes where they had felt that the professional had belittled them or trivialised their concerns by 'treating them as if they were stupid'. Others described their anger at being 'kept in the dark' by professionals who seemed unable or unwilling to inform, update and involve them. Others were angered by those who seemed generally uninterested in them and their child and who gave the impression of 'wanting to be somewhere else'. Participants also described a feeling of being 'abandoned' by services following the death of their child if no 'follow-up' bereavement or sibling support help was offered.

The participants who described the most negative encounters and who were most distressed and enraged by them were those who perceived the particular incident not as being a ‘lapse’ or momentary act of thoughtlessness by a professional, but as almost purposeful malevolence. Some participants noticed that the general attitude and approach of staff changed towards them when it became clear that their child was ‘palliative’. They sensed that hospitals often had a predominantly acute care focus that did not easily accommodate their needs. Parents and carers expected professionals to have what some accurately called a good ‘bedside manner’. They also expected that, when the decision was made to withdraw active treatment, the withdrawal would be done with sensitivity, respect and care for both family and child.

The most vivid memories of negative experiences for participants were of the times when they felt that staff (and these were often senior clinicians) had treated them or their children not merely with carelessness or thoughtlessness, but almost with callousness. While the participants’ accounts of their interactions with services and professionals were generally positive, it did seem that many parents or carers had such horror stories to tell. Some have been noted in earlier sections.

One parent angrily described a pattern of behaviour that she felt was akin to harassment by a member of staff in a children’s hospital, who continually phoned the family asking them to bring their child in for further tests and evaluation. This parent’s account reinforces the view that there is no higher court than perception. The charitable view would be that the person calling this family may have thought that he or she was being encouraging or ‘giving hope’. However, given the family’s detailed knowledge of the extent of their child’s illness and prognosis, and given the professional’s inability or unwillingness to listen carefully to them, an alternative possibility emerges, one that the parent subscribed to — that this was no more than crude emotional blackmail.

However, it would be a significant misinterpretation here to imagine that parents and families will forgive and forget anything with the passage of time. An important distinction seems to be noteworthy here. Participants may have been able to re-examine their anger at a professional who was ‘only doing their best at the time’, or who was perhaps ‘having a bad day’. However, it seems very unlikely that such a positive revision could take place where parents or families believe that professionals had not even been attempting to do their best and where their behaviour was perceived as having been motivated by a conspicuous lack of caring, or even contempt.

The area of participants’ negative experiences of services and professionals is undoubtedly difficult for both the participants and the professionals to recognise and engage with. Parents and carers generally appreciate and value health services and have immense regard for those who help treat and care for their child. They are often reluctant to criticise those who make the laudable choice to care for sick children. Staff, too, can be reluctant to accept criticism of their practices as they may feel that they are working immensely hard in a particularly demanding area and can do no more. Official responses to parents’ or families’ criticisms of staff and their reports of poor services tend to classify these as system rather than personal failures, in an attempt to avoid a ‘blame and shame’ culture. Thus conceptualised, the problem can be shifted from particular people and their interactions with families to a focus on wider policies, procedures and organisational culture.

Possible remedies then inevitably focus on global rather than personal interventions, for example, instituting communication skills training or hosting ‘customer care’ workshops. While such global efforts can have some positive effects, it is not clear whether they have an effect on the behaviour and approach of professionals who may be well known for repeated patronising or abrasive dealings with families.

- 3 **The terminally ill child in hospital** Most participants spent time in hospital, at least initially. This may have been a local or regional hospital or a specialist children's hospital. Participants' experiences of being in hospital with their children encompass such a range of activities, emotions and significant moments that it would be inappropriate to propose an overarching theory or theme to represent or explain such a diversity of experience. Some children were in acute care areas undergoing aggressive treatment — for example, chemotherapy and radiotherapy — while others had entered the palliative care phase much more quickly as curative treatment was not a viable option. Others were living with life-limiting conditions and entered hospital only during crisis periods or for regular monitoring and examination.

Some participants experienced hospitals and even children's hospitals as sometimes uncomfortable places in which to care for a child who was dying. The majority of participants in the study had more positive experiences of hospital and most were very appreciative of the professional skills and services that were available. Participants wanted their children to be cared for, and cared about, by health professionals. They became anxious and guarded if they felt that there was a possibility that their children might not be recognised as special and unique individuals, but rather as simply cases or numbers to be processed by the system.

Services that were lacking

In addition to asking parents to share their experiences of positive and negative aspects of services, the interview process also asked them for their views on particular services that they felt were missing or underdeveloped that may otherwise have been helpful.

Sibling support

Participants were clear that services and help for siblings were not as readily available as they could have been. Parents' and carers' accounts described how they struggled to manage all of the competing demands associated with caring for a seriously ill child but, in any attempt to balance priorities, there was never any doubt that the sick child was of paramount importance. For this and other reasons, parents described how siblings could find themselves in the difficult situation of being 'the 10%'. The demands of the sick child's care often meant that parents were unavailable, that normal routine was disrupted, and that normal family activities and promised time together could be cancelled at the last moment.

For one family, the demands of hospitalisation, travel and caring for their sick child led them to send their healthy three-year-old child to live with grandparents in another state. This sibling experienced great difficulties, however, when she rejoined her parents following her older sibling's death. At this time, the mother felt that there was no support for her daughter.

Parents noted a clear difference in the support available for bereaved siblings, for whom various programs and activities seemed available, and siblings whose brother or sister was still alive, for whom less support seemed to be available. Another family valued the service provided by the hospital school that offered help to siblings and not only to inpatients. For another parent, a nurse's willingness to take the sibling out for the afternoon made abstract notions of family-centred and holistic care very real.

Parents or carers and siblings also valued the peer support opportunities that were provided for siblings, such as camps, retreats and picnics. These fulfilled an important social function in bringing siblings together with other children who had experienced the loss of a brother or sister in an atmosphere of fun and enjoyment. However, the general impression conveyed by interview participants was that such programs and support for siblings were discovered and accessed more by luck than planning.

Support for fathers

A second area in which participants felt that support and services were lacking was help for fathers. The social and gender dynamics of families are complex but, when the stresses, complexities and emotional charge of a seriously ill or dying child are also factored in, then fathers' experiences become even more challenging to understand and respond to. Mothers, in particular, felt that fathers found it difficult to deal with the stresses of care associated with the children's treatment.

There is a pattern of social organisation in relation to children's illness and hospitalisation that is well recognised: mothers tend to be the partners who stay with the children in hospital and participate most directly in their care. Fathers tend to take on responsibility for other children in the family, for running the house and for continuing to work and sustain a family income (Darbyshire 1994). As with all generalisations there are exceptions, but this is the pattern that was reflected in the accounts of the parents in this study.

Concern was expressed that fathers' attempts to keep busy may not have been a particularly healthy way of dealing with a child's illness or with the loss of a child. Significantly perhaps, one father described his work as 'a sheltered workshop that you can hide in'. Other participants echoed this concern that fathers were 'burying themselves in work'. Many female participants in the study also believed that, as women, they were better at 'talking about things' and felt that men would go to great lengths to avoid being involved in 'talking stuff', such as counselling and support groups.

What also seemed important was that fathers could be comfortable in a 'normal' social situation again. Going on a day's fishing or having a beer and a laugh with a few mates does not seem to have the hallmark of the most sophisticated support program. However, given the trauma and turmoil that has turned these father's lives upside down and perhaps left them feeling that life at its very core is meaningless, such small victories should be celebrated as major therapeutic outcomes.

Participants described how fathers did talk, but in ways that differed from those of mothers. Mothers' and fathers' needs for help and support cannot be seen as competitive. Nor can they be judged as better or worse, or more or less legitimate than each other. A paediatric palliative care service grounded in an ethos of listening and responding sensitively to perceived needs would surely be more concerned with saying to parents or carers, 'We are here to listen and to help in whatever ways you would find most useful. What would you like from us?'

Perceptions of paediatric palliative care

The accounts of many of these participants tell us that paediatric palliative care has something of an image problem. Palliative care was perceived variously as meaning 'taking your child home to die', something that happens when the child goes home 'for the last time', 'giving up' and abandoning all medical or nursing care, particular people who suddenly appeared when a child was dying, and something synonymous with 'pain relief'. What the accounts of the participants in this study emphasised is that every aspect of this well-worn yet seemingly simple advice can be immensely difficult for parents and families: 'Take her home to what?' What is required at home for parents to be able to look after their dying child? What medication, what equipment, what support? What happens to the meaning of 'home' for parents and family when the home becomes, in effect, a child's hospice?

While there may be nothing that can be done to cure the child, there are emphatically things that can be done to help the child towards a death that is as comfortable, peaceful and pain-free as possible. There are

also important ways in which parents and families can be helped to anticipate and prepare for this death so that they may create memories of this time which are not entirely distressing or filled only with sadness, or worse, with guilt and recrimination. Some of the key issues raised by interview participants were:

- 1 **The presumption that things were done behind the scenes** For several of the parents interviewed, palliative care seemed to be such an inconsequential part of their experiences that they could not remember details of any palliative care services or personnel that had been involved, or indeed whether their child was in palliative care at all.
- 2 **Palliative care provided at the end of the child's life** Participants usually described palliative care as something that happened very much at the end of the child's life and, indeed, for some parents, the phrase almost signalled such an end. This experience graphically illustrates the importance of positioning palliative care services as an integrated element of the care of seriously ill children. When palliative care is tagged on as an afterthought, or proposed as an act of hopeless desperation because 'nothing more can be done', it is always possible that children and families will identify palliative care staff and services as nothing more than the personifications of fear, 'medical failure' (see Charlton 1996), and death itself.

One parent described how offers of palliative care support came too late, at a time when the family had had enough of different people and different services impinging on their lives. Another parent voiced the concern that palliative care was something that would not support, but rather 'take over' her role as the child's prime carer.

- 3 **Positive outcomes** Participants who had help and support from a specialist paediatric palliative care nurse generally described this as being the most significant and valued aspect of their coping with their child's palliative care and death. Such a service took different forms, from the presence of a larger paediatric palliative care team to that of a single paediatric palliative care coordinator. It was important for parents and carers that such a guide was both knowledgeable and skilled in all of the various technical aspects of palliative care. It was also important that that person could help with both the parents' and child's emotional and social needs and was experienced in caring for sick children. Perhaps what participants valued most about having access to an effective paediatric palliative care nurse was that this person was able to act essentially as a case manager, as a focal point for all questions, problems, contacts, practical assistance, advocacy, bereavement support and, in short, anything that they needed.
- 4 **Use of voluntary and other services** Parents and carers did not restrict their search for information, help and support to health services, and several participants described the valuable assistance and support that they had received from various non-statutory organisations, support groups, charitable trusts and other support organisations. The range of support that they accessed via these organisations included respite care, bereavement support, sibling support camps, 'buddies/mentors' for the sick children and siblings, and helper/carer assistance at home. Aspects of these organisations' support that were highly valued were their inclusiveness in catering for children from any 'diagnostic group' and that parents and carers had the opportunity to talk to others who had lost a child through serious illness.

Caring for the child at home

Children with life-threatening conditions often spend considerable time in hospital for tests, treatments, assessments and more. However, these children still have their 'normal lives' at home. For many families, this distinction between home and hospital can become blurred as many aspects of the children's treatments

take place at home. Aids and machines take over rooms, medications and equipment fill the cupboards and, when the child's death seems imminent, many parents choose to have the child die at home rather than in hospital. Parents differed in the extent of information and preparation they needed to enable them to care for their children at home, but a common perception expressed was that this was something that you learned 'as you went along'. One family described starting as if it were from 'ground zero'.

Physical demands of care

Participants were asked to tell us what it was like for them to care for a seriously ill or dying child at home. While those who chose to do this were sure that they had made the correct decision, their accounts of providing this care and support were almost consistently stories of constant vigilance, difficult physical care and parental exhaustion. Ironically, perhaps, 'exhaustion syndrome' has now been identified in the research literature (Astudillo and Mendinueta 1996), but this is exhaustion as it affects mainly palliative care staff. The demands of providing care for a child were often so pressing that either or both parents would have to either negotiate a protracted period of leave or resign from their jobs. This was not an easy decision to make but neither was it especially difficult, as parents would clearly place their children before their jobs.

Support in caring for the child at home

Participants gave particularly perceptive accounts of the difficulties involved in this process. Central to their explanations was the concept of the social 'dynamic' of the home. What they highlighted here is that providing meaningful help and support is not simply a matter of allocating any available person to go to the house to help out for an allocated number of hours per day or week. One parent explained this particularly well when she articulated the subtleties of having new or strange people in your home and in sharing the care of your dying child. For this family, help from 'that woman' would have been no help at all but rather a further encumbrance and a drain on the parents' energies, which were of course focused on their child and the remainder of their lives together. Put bluntly, this limited time was far too precious for parents to waste a second on anyone or anything that did not truly matter to them.

Other participants described the vastly different positive and negative experiences that were possible when having 'strangers in the house'. Families felt the tension here between needing and wanting help and support that would enhance their ability to care for their child and themselves, and simultaneously being guarded and apprehensive about allowing 'just anyone' into their home and family.

Respite care

Being the parent or carer of a seriously ill or dying child who may well have very complex and demanding care needs can be difficult and demanding. While this is undoubtedly a labour of love, it is a labour nevertheless. Parents and carers highlighted the multiplicity of demands created by their child's condition. To the naïve or unthinking these may seem to be similar to the demands that all parents face, but the differences are significant. For example, all parents feed and nourish their children but not all parents have to take three to four hours with a teaspoon and suction machine nearby to ensure that their child eats breakfast. Being the parent of such a child is to be almost in a state of 'hyperparenting', in which so many of the normal and everyday aspects of caring for a child or a teenager are intensified and complicated to the point that nothing ever seems to be simple. And layered over this life is the omnipresent knowledge that it is very likely that this child will die.

Respite care was clearly a flexible term for participants, and it could mean anything from receiving ‘home help hours’, when someone sent by a support organisation or the local council helps with housework, shopping and so on, to the more usual sense of respite when either the parents or the siblings and sick child are given ‘a break’ of some description. On the surface, respite care seems unproblematic but, as with most aspects of children’s palliative care, it can be more complex. Having someone come to the home to help with cleaning, shopping and cooking for the family so that the parents or carers can attend to the needs of sick children or be at the hospital with the children is an excellent idea. However, the acceptability and success of this support is dependent on a wide range of complex family, social and emotional dynamics and perceptions. Some participants reported that they tried so hard to manage or ‘battle on’ by themselves and did not want to ask for help until they found themselves having to admit that they were ‘not coping’.

If respite is to be meaningful and to fulfil one of its functions — to let parents, carers or siblings have time together and enjoy a break — then it is essential that parents and families have faith and trust in the people and the service who provide the respite. If this trust is absent, then the reality of the respite break will be that the parents or carers will spend their time away worrying about their children and whether they are being well cared for. How respite care is offered and conceptualised is also important, for behind the kindly title lies the shadow of a suggestion that, if parents or carers need or ask for respite care, they are ‘not coping’ or they are unable to care for their children. If such a perception is created or entertained, then respite care looks a much less acceptable option and soldiering on and coping heroically can instead seem the ‘right thing to do’, rather than guiltily enjoying yourself in the absence of your child.

An alternative approach to respite care could be to offer this to families as a chance for sick children to have an enjoyable and valuable time in the company of others and have a break from their parents. Respite could also be an important opportunity for the siblings to enjoy some special time with their parents.

Financial support, benefits and allowances

Caring for a child with a serious illness or complex disorder creates extra costs for families. In addition to the direct costs of equipment, medications, travel, hospital car parking, ‘quick and easy’ convenience meals and ‘take-aways’, childminding to enable clinic/appointment visits and so on, there are the indirect costs of lost parental incomes and more. Families may have understood that financial help could be available or, in applying for help, they may have received assistance from a social worker, another parent or carer or someone else who knew the system and its intricacies.

Unfortunately, the families in this study had almost uniformly negative experiences of dealing with Centrelink and the benefits system. Generally, they perceived this to be yet another hurdle to jump, a largely unresponsive bureaucracy whose systems and processes made their applications difficult, time consuming and humiliating. Ironically, when participants did mention a positive aspect of Centrelink and the benefits system, this tended to be in relation to how they were treated when they contacted an office to inform them that their child had died.

Parents explained that completing application and assessment forms was potentially frustrating and painful. The frustration arose when the forms did not seem to accommodate the whole story of the child’s life and care needs, but asked only for context-stripped ‘objective’ data about ‘functioning’. What is involved here is not merely the insertion of facts into a form, but a public process of detailing the child’s deficiencies and ‘failings’. When parents and carers are often trying so hard to focus on hope, on positives and on normalising their children’s lives, it can be dispiriting and distressing to have to accentuate problems and deficiencies in order to qualify for financial or other support.

The child's death

It seems presumptuous in the extreme to claim in a report to be able to describe parents' experiences of being with their children as they died. The phrase 'there are no words to describe it' has been drained of all meaning by constant use in this context. There are many questions that surround a child's death that seem almost impossible to ask, let alone answer: is the child's death 'worse' than his or her illness or treatment?, can there be such a thing as a good death?, can anything prepare parents for their child's death?, what does and should a child know and understand about his or her own death?, and no doubt many more. Yet participants in these interviews often did manage to describe the indescribable with such a powerful and simple poignancy that these accounts deserve consideration in all policy and service provision planning.

Talking with the child about death

This is a contentious and difficult issue and one which parents or carers dealt with differently according to their beliefs and knowledge of their own children. Some tried to be as honest and open as they could while others chose not to tell their children until death was very near.

It would be simplistic and mistaken to assume that this is simply an issue of honesty, that parents who tell their children everything are being honest and that, as a result, those who choose not to are being deceitful. There can be very few either/or issues in children's palliative care and the question of telling children that they are dying is another example of the complex dynamics at work within children, parents and families. It required interview participants to make the most subtle and sensitive decisions about whether, when and how to discuss dying and death with their children.

Discussing dying with children and perhaps telling them that they may well die soon is not solely a matter of passing on information. This is an area that involves profound issues such as hope, quality of life and the child's spirit. Participants described the dilemma they experienced: they wanted to be honest with their children and help them understand what was happening to them, while trying to avoid destroying their hope for recovery, making them fearful or damaging their ability to enjoy the remainder of their lives. Participants conveyed this difficulty well. The question of whether to tell the children about death seemed not to become any easier with the children's growing awareness of their own vulnerability and mortality. Participants described how they 'sensed' or 'knew' that their children knew that death was close, but that this often remained unspoken and unacknowledged by both.

Participants also recounted mixed experiences of the help or otherwise that they received at this time. This was one of the key periods during which parents and carers said they really needed help and advice about how to deal with both their children's deteriorating condition and their own increasing despair at the prospect that the children were soon going to die. Participants who encountered services with little sensitivity or flexibility were surprisingly not distressed by clumsy attempts to help.

Place of death

Most of the children died at home but others died in hospital or in a children's hospice. Participants had various reasons for choosing the place of death. Many wanted the child to be away from the reminder of hospitals and treatment and to be home, surrounded by family and familiarity. Other parents preferred a health care setting, often because they were afraid of death and what it would be like, and felt unsure that they could deal with it on their own.

Nearing death

Parents and carers reported various factors that made them believe that their child's death was near. The child's condition deteriorated, they became 'sicker', lost energy and vitality, became more listless and tired, showed physical signs or symptoms and perhaps experienced an altered consciousness. One aspect of the child's deterioration that concerned parents and carers was that services and staff seemed to 'write off' their child or suggest that there was no point in treating them further, even for symptom relief. Some parents also mentioned unusual moments when they felt that their child was experiencing something akin to a 'near-death experience' in which the child would seem to be listening or talking to someone.

Moment of death

Parents' descriptions of the actual moment of their child's death varied and included memories of being afraid and distressed, of feeling that the child was at last at peace and even of recalling that the moment had its own beauty. Most health professionals want to 'do the right thing' for parents but, if a particular approach to parents and families, however well intended, becomes accepted wisdom and is taken routinely and procedurally, there will always be the possibility that this may be inappropriate and unhelpful for some families.

One family's account of the fear and uncertainty that they experienced as their child died (paradoxically in a children's hospice) highlighted once again that there can be no 'one-size-fits-all' homogenised response to supporting families at this time. This family did not wish to be left alone with their child at the moment of death and were highly stressed when staff felt they needed time on their own. Whether staff in this case felt that they were doing the right thing by respecting the parents' privacy or by letting them spend their last moments alone with their child, or whether they even felt uncomfortable and fearful at this time cannot be ascertained, but the end result was that this family's needs at this time were not met. They were afraid, uncertain, vulnerable and distressed and, despite their specific requests for staff to 'walk with them' and support them at this time, such help was not forthcoming. How different their memories of their child's death might have been had staff said, 'We do not know what is best for you at this time, but we are here to support you however we can. How can we help?'

Others described how they received help to create the rituals and memories that many parents and carers describe as being very important and sustaining for them at this time. These can be as simple and as profound as being invited to (as opposed to being 'allowed to') help bathe and dress the child's body and or creating significant mementos.

Several parents spoke of the importance of giving their child 'permission' to die. This was a profound acknowledgment by parents that recovery was no longer possible and that death was inevitable. However, there was no sense in the parents' accounts that hope had been abandoned. It was, instead, modified and the hope was now that that the child's death would be as peaceful as possible. With such permission giving, the parents clearly hoped that the child would feel more at ease in leaving. Perhaps this permission was also for parents themselves, so that they too would be more able to face the moment of loss when it came.

Grief and bereavement

The grief of losing a child was described as such a cold, helpless and empty feeling that parents and carers wondered if they would ever be able to experience anything akin to normality ever again. They had not only lost a child but an entire world of meaning. Nothing would ever be thought of or

experienced the same way again, from personal values and assumptions about life and the world to everyday thoughts and activities. The participants recalled their experiences of feelings that are so consistently reported in research on grief and bereavement. These included numbness and shock, profound sadness and tearfulness, physiological symptoms, and even suicidal thinking in one mother motivated by the anguish of not knowing 'where her child was' and wanting desperately to be with the child again.

Time and grief

When they were asked about the time immediately following the child's death, participants spoke of being in 'shut down', or 'living in a blur' as they tried to describe the perceived unreality of the new world or state of being that they had entered. Several commented on the timing and phases of grief as they tried to describe how particular times may have been worse than others, while always acknowledging that 'there's not a second of the day that goes past that I don't think about her'. One parent said that the period of around four to six weeks after the child's death was particularly difficult, while others described the second year of bereavement as especially difficult as this can be a period when the 'numbness' and 'shut down' can wear off to reveal the wound, as raw and painful as ever.

Bereavement support and feelings of abandonment

Participants' concern highlighted the need for a children's palliative care philosophy and practice that sees bereavement support and family follow-up as an integral part of good paediatric care and specifically of paediatric palliative care practice, rather than as an erratically available optional extra. Some participants described a sense of being abandoned (see, for example, James and Johnson 1997, p 90) or forgotten by services after the child's death, suggesting critically that care seemed to stop either at the hospital door or at the end of the child's life. Such feelings spoke to the complex and intense nature of the relationship built up often over months or years between parents or carers and the staff and facility where their children were cared for.

This relationship was significant and meaningful for those interviewed, who felt that they and their children truly 'meant something' to the staff who had worked with them. These were staff who had been with them and their children through the tough times and the peaks and troughs of investigations, treatments, remissions and relapses. Participants felt that such a partnership had forged a bond of friendship between them and staff and may have felt abandoned and even betrayed when, following the child's death, there was no contact or follow-up from the staff, ward or unit.

Summary of findings

This study sought to investigate participants' feelings about the:

- areas in which they found existing services to perform well;
- areas in which they experienced difficulties and where services were available but did not meet their needs;
- areas in which difficulties were experienced but there were no services available;
- issues that contributed to their confidence in the service or otherwise;
- points at which they most needed services;

- information they required and the extent to which that information was provided, available and useful; and
- factors that would improve current services.

This chapter has been presented in such a way that the findings reflect the major thematic areas that emerged from the participants' accounts. In the following section, each aim is addressed in turn and each of the first six sections also includes participants' suggestions about how current services might be improved.

Researchers presenting comparatively small-scale qualitative studies such as this are always cautious not to extrapolate beyond the capacity of the data. It cannot be assumed, for example, that this study represents the experiences of all families who have lost a child, or that this is the definitive account of parents' experiences. What we can say is that we have listened carefully to a broad cross-section of parents and carers whose children had a wide range of life-limiting conditions, and that their accounts of palliative care and the loss of their children have been carefully and sensitively presented.

Areas in which participants found existing services to perform well

One of the notable features of the participants' accounts which is germane to each aim is that services seemed haphazard and erratic. Some families found existing services to be sensitive, responsive and valuable while others found them to be lacking in services or in the level of caring and compassion shown.

Parents and carers clearly appreciated services that were coordinated and cooperative, as this smoothed away many of the problems and difficulties identified by other participants unfortunate enough to have to 'fight for services' or to 'tell the same story' to a range of different service providers who seemed unable to communicate with each other.

Participants especially valued services in which a skilled, knowledgeable and caring 'key worker' or 'case manager' was available to help them, and that person was introduced as early as possible. Some parents especially mentioned the paediatric palliative care nurse in this respect. The person in this role was able to act as a point of reference for the family, so that family members could liaise with one person who was readily available, easy to contact and who had the specific paediatric and palliative care skills required to respond to their needs. This person also had the professional and local knowledge to act as advocate for the family and liaise with the other agencies and interdisciplinary team members involved in the child's care.

Other services which were deemed valuable by parents, carers and children were support organisations where they could often talk with others who had been in similar situations, had 'been there' and who could share experiences. This was crucially important for parents as, even with the best will in the world, they did not believe that professionals who had not experienced the serious illness or death of their own child could truly understand what they, the parents, were experiencing. These support organisations were especially valued for their psychosocial care and for the facilities they offered.

Areas in which participants experienced difficulties and where services were available but did not meet their needs

There were several service areas where participants experienced difficulties. Centrelink and the benefits system was almost always cited as a particularly difficult and inflexible service for parents to access and from which they could benefit. The situation was more positive for parents or carers who had a social worker or other professional support to help them navigate through this system but, for those tackling this on their own, it was almost too hard. As was mentioned above, the most positive reports of Centrelink's service related to its staff's sympathetic attitudes and actions after the death of a child.

Diagnostic services and the process of diagnosis was clearly an area of contention for many participants. Most of their dissatisfaction stemmed from the approach of the professionals charged with either testing the child or breaking the news. Parents and carers did seem to understand the difficulty of making a definite diagnosis, especially with rare and unusual conditions, but they were rightly far less understanding of insensitivity or rudeness on the part of those who controlled the diagnostic testing and disclosure processes.

Some participants experienced difficulties with the hospital system generally, feeling that it was not conceptually attuned to the needs of a child with a life-limiting illness. They felt that the acute care, treatment and cure model of health care was not best suited to their child's needs. They did not need to be medical sociologists to understand that they sometimes felt as though their child was a visible accusation of the failure of the system to bring about cure and recovery. If a hospital or health system is to have cure and recovery as its benchmark of success, it is perhaps not difficult to understand how easy it may be for children who do not meet this benchmark to be seen as failures.

Within palliative care, this is often critically caricatured as the 'there's nothing more we can do' response. Given the lack of an integrated, interdisciplinary, specialist-trained and available paediatric palliative care service that some participants experienced, this often ridiculed response may be a more accurate reflection of services than we would wish to imagine.

Participants had many suggestions for the kinds of services that they would like to see in place. At an organisational level, they wanted an integrated, user-friendly, cooperative, interdisciplinary, flexible, compassionate service, not a fragmented, labyrinthine collection of different services that did not speak to each other and were difficult to discover, access and use.

They also wanted a relationship with this service that was more collegial, holistic and more of a partnership. They wanted their unique and individual child to be at the epicentre, but also needed a service that understood the needs of the family as a whole. They understood very well that this was a journey that they were undertaking that called for a more involved and sustained relationship with health care providers. In this respect, the essentially passive terms 'consumers' or 'users' as applied to these families become unhelpful and inadequate. Parents and carers saw themselves as being infinitely more than users of services or as people who consume health care. Many felt that they were their own child's case manager and, as such, they wanted a far more involved and collaborative relationship with staff and services.

Areas in which difficulties were experienced but no services were available

There were several aspects of service provision that participants identified as being necessary but currently unavailable or otherwise difficult to access. Support services for fathers and siblings were the most pressing of these mentioned. Most participants in the study were mothers and they were very concerned that their partners or husbands were having to cope with the trauma of their child's illness or the pain of the death with little or no support. There was a very clear sense that some conventional support or counselling — 'talking approaches' — that may have been valued by mothers, would have minimal or no appeal for fathers.

Parents were also very concerned about their other children and often felt that these children were 'doing it tough' as the brother or sister of a dying or deceased child. While some support and peer organisations provided valuable support, there seemed little in the rubric of statutory paediatric palliative care services that catered for their needs.

While we did not specifically target rural families in this study, particular families acknowledged that living in a rural area aggravated many of their problems related to accessibility, costs, travel, disruption of home life and so on.

Issues that contributed to participants' confidence in the service or otherwise

Participants felt confident in a service when they felt confident in the staff and people with whom they met and interacted. In a very real sense, the value and acceptability of a paediatric palliative care service stands or falls on the quality of every encounter and interaction between a particular parent or carer, child and family and a member of the service's team. This may sound simplistic but the participants' accounts in this study strongly support such a perspective.

Where families had developed a warm, caring, friendly relationship with health professionals, they were much more likely to have the confidence to ask questions, to discuss their preferences, wishes, hopes and fears, and to ask for and receive help. By contrast, families whose confidence in a health facility service had been shaken — either by a single negative encounter, or by multiple disappointments with the service's ability to understand and respond to their needs — were more likely to give up and look for help elsewhere.

Parents' and carers' negative experiences with professionals whom they perceived to be rude, abrasive or insensitive were significant and important for them, and yet they were in a position where they were comparatively powerless to make their feelings known or to take any action. The power and dependence relationships at work here make it very difficult for a parent to risk upsetting or alienating a person on whom their child's life may depend.

The onus is thus clearly on health professionals to address this issue. They must create the policies and practices that send a clear message from the organisation to all staff, from first level nurse to consultant surgeon, that serial insensitivity or habitual rudeness and brusqueness on their part is unacceptable, and that interpersonal approaches will be monitored and taken as seriously as diagnostic and treatment abilities. Staff are already accustomed to undertaking 'critical incident reviews' if a clinical or treatment-related problem has arisen. Such a review mechanism could readily apply to critical interpersonal incidents.

Participants' confidence was also enhanced when professionals demonstrated not only care and compassion but also showed that they had specific skills and knowledge of both children and their needs and palliative care in its most holistic and family-focused sense. Parents and carers wanted 'the best of both worlds' in their paediatric palliative care staff, to which they are surely entitled. A general palliative care service was too easily 'freaked out' by dying children and did not have the specific knowledge and orientation to understand the special needs and dynamics of children, siblings and parents. Similarly, a general paediatric service may have lacked the specific understanding and skills related to children's palliative care that were so essential if the physiological and psychosocial needs of the child's dying trajectory were to be recognised and responded to.

Points at which services were most needed

Participants may well have answered this point by saying 'all of them', for it is difficult to imagine a time when they would not have valued skilled help and support, even if it were only in the background, ready to be called upon if required. The parents' or carers' accounts highlighted several difficulties that were created when palliative care was introduced either too late or in such a way that it was unfortunately perceived as being a 'death service'. Participants in this study have clearly indicated that their questions, concerns, anxieties and care needs did not start at the point where their child's curative treatment stopped, but rather from the moment that they first had serious concerns that their child may have been ill.

If palliative care is proposed, even subtly and unintentionally, as ‘the failure stage’ in a child’s care, to be wheeled in ‘when there is nothing more that can be done’, it should be no surprise that parents, family members and children balk at its mention. An alternative and altogether more promising approach to palliative care for children and young people could be taken if the philosophy behind the widely accepted Association for Children with Life-threatening or Terminal Conditions and Royal College of Paediatrics and Child Health definition of paediatric palliative care were adopted and operationalised. This definition, from *A guide to the development of children’s palliative care services* (RCPCH 1997) says:

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

The defined life-limiting conditions are those for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and treatment failure. Four broad groups may be delineated:

- life-limiting conditions, those for which there is no reasonable hope of cure and from which children will die. Many of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers (for example, cancer and irreversible organ failures of heart, liver or kidneys).
- conditions for which there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible (for example, cystic fibrosis and muscular dystrophy).
- progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (for example, Batten’s disease and mucopolysaccharidosis).
- conditions involving severe neurological disability, which may cause weakness and susceptibility to health complications and may deteriorate unpredictably, but are not usually considered progressive (for example, severe multiple disabilities such as those that follow brain or spinal cord injuries, including those of some children with severe cerebral palsy).

Such a definition and conceptualisation directly challenges the view that palliative care is a defeat, an absence of cure or a passive acceptance of death. It would be difficult for a parent or child to read this definition and feel that a service driven by such a vision of palliative care had ‘given up on them’ or that ‘there was nothing that they could do for them’.

This understanding of paediatric palliative care also challenges the limited medical notion that recovery and cure are the sole markers of successful management and care. Of course, this is not to suggest that active and successful medical treatment is undesirable or of minimal importance. This is crucially important, but it is not all important and the answer is ‘a great deal more’. The ‘more’ means that, while parents and carers appreciate medical, surgical, nursing, physiotherapy and other professional skills, they expect these to co-exist with the human skills that enable them to feel that they are cared for, cared about, respected, confident partners and colleagues in this journey that they are taking with their child.

Information required and whether it was provided, available and useful

Participants' accounts in this study suggest that they understand the distinction between information, knowledge and understanding. From the first inklings that something was not well with their children, they wanted and needed information. They needed information about the condition, about their children's treatment and management, and also information about how this was going to affect all of the family.

Parents and carers wanted information, but they also wanted information that led to understanding and this was not always available. For many parents and carers, communication with health professionals, especially doctors, left them feeling uninformed, confused or 'stupid', as the information was not explained in ways that helped them to understand it.

The internet has undoubtedly changed the nature of medical information and many families routinely used the net to gain information that would, until recently, have been unobtainable. This resource is also helping parents, carers and children to share information about treatments, programs and all aspects of the child's illness with others in online support groups.

Participants expressed a need for specific information dealing with death and had difficulty finding people who would tell them directly, clearly and sensitively about their child's dying — what this would be like and what they could do, as parents or carers, at this time. Vague allusions to their 'just knowing' were not deemed helpful at this time.

Many participants in this study found the most valuable information was obtained by 'word of mouth' from either palliative care staff whose views and experience were respected, or from other parents, carers or support organisations who had 'been there', and who had first-hand understanding of what the family may be facing and experiencing.

Consumer views in the wider paediatric palliative care context

This report of parents' and carers' experiences is timely in the development of paediatric palliative care services in Australia. A recent Australian review said that there has been a 'lack of research data on the experiences of families and carers of palliative care patients' (Wilkes, Tracy and White 2000). This consumer interview study helps redress that lack and strengthens the body of international research which demonstrates that existing approaches to paediatric palliative care are inadequate in several important respects.

Our review, and particularly its consumer interviews section, has an explicitly pragmatic and practical impetus: to influence and stimulate action, specifically the development of palliative care services for Australian children, young people and families that will be at least the equal of any other service in the world. However, while practicality is commendable, this must be grounded in a clear research-based understanding of the lives, experiences and perceptions of those families served by paediatric palliative care, and also in an understanding of the organisational and professional contexts of health professionals' practice and health care provision.

A striking aspect of this study has been the congruence between this work and other recent Australian and international studies of parents' palliative care experiences. While this is notable, it is scarcely surprising as numerous studies have shown that there are elemental human emotions and shared experiences that bereaved parents across countries and cultures share with each other (Davies et al 1998).

A 1997 study from South Australia (Darbyshire, Haller and Flemings 1997) found similar parental concerns: that information was inadequate and unclear, that services were fragmented and accessed often by luck, that palliative care as a concept and service was poorly understood, and that the caring attitudes and approaches of staff were extremely important.

There have now been worldwide calls for improvements in palliative care services for children. These calls have been stimulated by research, such as the current study and others, that has clearly shown gaps in paediatric palliative care provision and that the quality of care varies between none and exemplary. In the USA, a recent study (Wolfe et al 2000) found that parents of children who had died of cancer believed that '89% of the children had suffered "a lot" or a great deal from at least one symptom', such as pain, fatigue or difficulties with breathing. The researchers (Wolfe et al 2000, p 326) concluded that many have substantial suffering in the last month of life, and attempts to control their symptoms are often unsuccessful. Greater attention must be paid to palliative care for children who are dying of cancer.

Many parents and palliative care professionals would also add here that such attention must also be paid to the wide range of other children, for example, those with degenerative neurological and metabolic disorders (Hunt and Burne 1995, Davies 1996, Steele 2000). The National Hospice and Palliative Care Organisation in the USA has issued a 'call for change' to respond to the needs of the estimated 45,000 or more dying children who receive no specialist palliative care service in that country (Rollins 2002, Rushton and Catlin 2002). An overview of similar recommendations and statements is available in a report by the Institute of Medicine called *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families* (Institute of Medicine 2003). In the UK also, the joint recommendations of the Royal College of Paediatrics and Child Health and the Association for Children with Life-threatening or Terminal Conditions (RCPCH 1997) have been widely accepted as a basis for best practice in providing paediatric palliative care.

What is strongly supported by such statements and initiatives is that, for paediatric palliative care, the time for action has most assuredly come and there can be no sound rationale for delaying the process of transforming services for children with life-limiting conditions. It is commonplace for researchers to conclude reports with an acknowledgment that 'further research is needed'. In this case, this is only partially true. No further research is needed to show that current services fall short of what this most vulnerable group of children and their families need and deserve. No further research is needed to tell us what the principles and fundamental approach of a valued paediatric palliative care service should be.

Where research will continue to be vital is in improving our knowledge of effective and valued treatments and supportive interventions for the wide range of children and young people of different age groups, cultures and backgrounds, in deepening our understanding of the worlds of children and families who face such a life-limiting illness, and in evaluating new services to ensure that they meet the ultimate test of quality assurance. Research can help to ensure that we have what each of us would wish for in a service if our child was dying.

Chapter 7

Best practice models of paediatric palliative care



This chapter discusses the accepted best practice models of paediatric palliative care that take into account the unique needs of children and their families in need of this service. These needs have been identified through our literature review, and the information obtained from service providers in our case study review and from families in our consumer interviews.

Issues unique to providing paediatric palliative care

There are common problems in palliative and end-of-life care for children and adults. These include the requirement for well-coordinated, complex care from multiple service providers that is provided in a compassionate, competent and consistently delivered manner, one that is congruent with both patient and family needs. However, some problems are unique to providing paediatric palliative care services and these are summarised below.

- 1 **Developmental differences** From a developmental standpoint, children should not be considered as small adults. When providing palliative care services to children, it is important to take into consideration the developmental differences between infants, children, adolescents and adults, which may affect diagnosis, prognosis, treatment strategies, communication and decision-making processes.
- 2 **Greater prevalence of rare conditions** Many children who require palliative care are those born with rare medical conditions, which result in significant uncertainty about diagnosis, prognosis and medical treatment. Even when children have more common problems, their physiological resilience often complicates predictions about their future. This uncertainty creates fear, anxiety and apprehension for both medical professionals and families as the potential benefits and disadvantages of various treatment options are considered.

In summary, while the general principles of palliative care apply to both children and adults, children's care is different and certain additional values apply. These are outlined in the conceptual model presented below.

Conceptual features of a best practice paediatric palliative care model

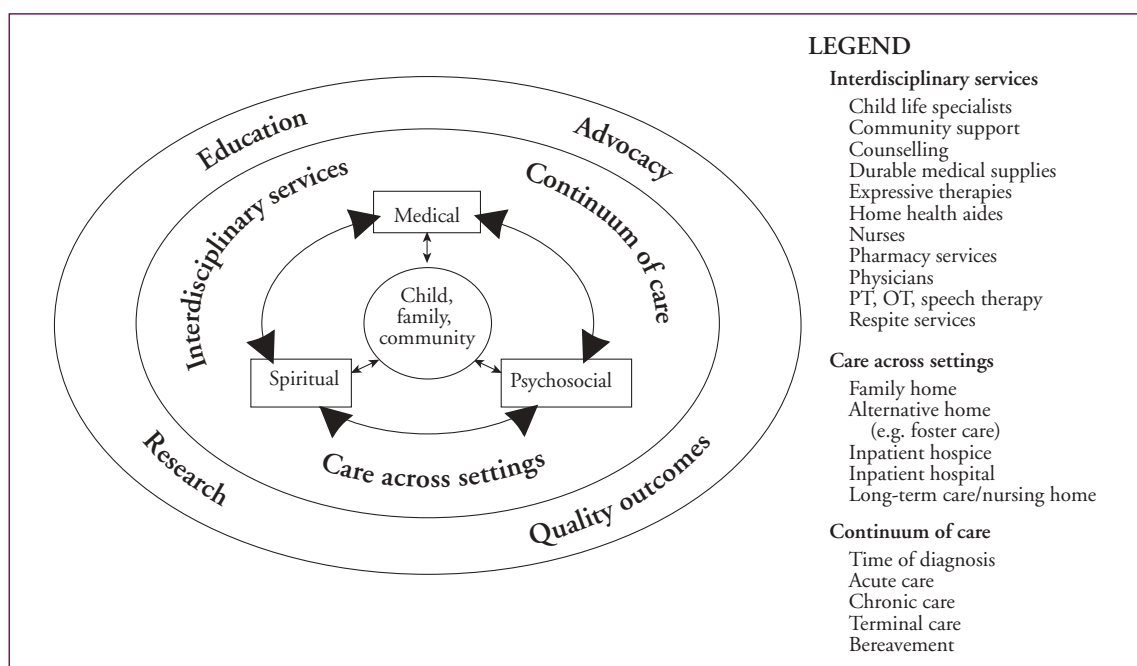
As previously discussed, there is now a growing global emphasis on implementing improved models of care that provide for an accessible, integrated, interdisciplinary approach based on principles such as:

- respect for the dignity of patients and their families,
- access to competent and compassionate palliative care,
- support for the caregivers,

- improved professional and social support for paediatric palliative care, and
- continued improvement of paediatric palliative care through research and education (Preboth 2001, p 569).

Our review of the literature has identified an ideal model of paediatric palliative care (ChIPPS 2001) that is schematically presented in figure 6 below. This model focuses on meeting the needs of children, families and communities by integrating all aspects of care within unified goals and offering interdisciplinary, holistic services. Within this framework the best practice models of paediatric palliative care are moving away from a rigid demarcation between curative and palliative care and are focused on capitalising on the natural synergy that can exist between them.

FIGURE 6: PROPOSED PAEDIATRIC PALLIATIVE CARE MODEL



Source: ChIPPS 2001.

At the centre of this model are the needs of the child, family and the community. The care is delivered in a home, in a community-based facility or in a hospital. Key elements of the program are tailored to meet the needs of the child and family, with packages of care being added or removed in accordance with changes in the child's condition. The implementation of this model of care should not be dependent on forgoing other valued elements of care, nor contingent upon a certain prognosis of the time of death. There is no single care delivery model that will work across all communities but, instead, the model of care should take into account the availability of existing resources and programs and build on what is currently available without duplicating services.

This model presents a significant opportunity for specialist paediatric hospitals and community-based service providers to work collaboratively towards changing the culture of the care of children with life-threatening conditions. It also offers them the chance to develop systems that are integrated across the continuum of care and are both family and community centred.

Focus on service integration

In an effort to accommodate the diagnostic diversity and prognostic uncertainty encountered in paediatric palliative care, definitions of palliative care are growing increasingly broad and inclusive. In chapter 6 we examined the definition of paediatric palliative care according to the Royal College of Paediatrics and Child Health and the Association for Children with Life-threatening or Terminal Conditions (RCPCH 1997). The World Health Organization and the American Academy of Pediatrics both advocate a model of palliative care that is relevant during the early stage of illness, and should be utilised in conjunction with other interventions that are aimed at prolonging life. The academy goes even further, proposing an integrated approach where palliative care is offered at diagnosis and continues to be provided over the course of the illness irrespective of the clinical outcome.

This does not necessarily mean that a dedicated palliative care service should become involved at diagnosis. Rather, it means that the paediatric palliative care team's brief should include educating health care colleagues about aspects of palliative care such as advanced communication skills, decision making, care planning and so on. This is because much of the early management of children with palliative care needs is provided by paediatric health professionals or subspecialist areas. From the point at which the family encounter the very first palliative care team member, impressions are gained which set the scene for future discussions and supportive interventions.

Optimal care at this time is vital to helping children and families meet the challenges that lie ahead. To facilitate this care, it is essential that workers in paediatric palliative care are able to influence the broader system to:

- improve understanding among paediatric health care professionals of the broad nature of palliative care (that is, that it is not just terminal care); and
- provide all health professionals with the skills and knowledge they need to manage this patient population well.

Key study findings supporting the implementation of an integrated model of care

The following is an overview of the imperatives that support the implementation of best practice-based, integrated, paediatric palliative care models.

- 1 **Integrating service across the continuum of care** The evidence indicates that best practice for paediatric palliative care requires the combined expertise of health professionals from both the acute and community-based health sectors (including disability and education) and also health professionals working in the paediatric and palliative care sectors. It will be important to ensure that paediatric palliative care is recognised as a subspecialty in its own right, consistent with global trends.

Study findings: On the basis of our case study reviews and interviews undertaken with families we found that coordinated and integrated paediatric palliative care services are needed. The focus should be on delivering a paediatric palliative care program that can best meet the needs of children and families by integrating all aspects of care under the same goals and offering interdisciplinary, holistic services. This would ensure that the range of services can permeate the health care system to deliver a comprehensive service with a focus on total client management, and provide families with a range of options from which they can make informed choices about the future care of their children.

This model of care would require a shift from the current demarcation between curative and palliative care to develop a system that can make the continuum of care seamless. This view is supported by our literature review findings and is in line with the innovative models of care being developed in the UK and the USA.

- 2 Providing appropriate home-based support** Internationally and in Australia there is an increasing emphasis on giving families the option to care for their children in their homes. Providing home care means that families stand to benefit from the existing and relatively well-developed, although largely adult-focused, community palliative care infrastructure.

Study findings: In our case study reviews and interviews undertaken with families we found that a high proportion of the affected families had a desire to care for their children at home. However, it will be necessary to ensure that there is an appropriate support infrastructure available, such as adequate respite facilities, to meet families' needs in this regard. This view is also supported by our literature review findings and by the service improvement initiatives that have been undertaken in Australia and overseas (as discussed in chapter 3 of this report).

- 3 Providing a coordinated, flexible and responsive program** Children with a life-threatening condition tend to move between places of care (home, hospital and hospice) as their needs change. To achieve a seamless transition, the paediatric palliative care system has to be flexible and responsive to the needs of the children and their families. One reason that this care coordination is so important is that many services and agencies are involved, across a range of care settings.

Study findings: Interview participants repeatedly commented on the frustrations experienced in coordinating the care needed for their children. Service providers also indicated that issues of care coordination and improving the continuity of care presented significant challenges, particularly for children with complex chronic problems that required inpatient, home and community-based support services from a range of health professionals and agencies often separated by geographic and even cultural differences.

Some service providers have clearly been working towards improving the coordination and continuity of their care using interdisciplinary teams and collaborating with community-based service providers. However, further work is required to establish collaborative procedures for palliative, end-of-life and bereavement care, and to support coordination, continuity and the timely provision of information within agencies and across the continuum of care. This view is also supported by our literature review findings and by the service improvement initiatives that have been undertaken in Australia and overseas.

- 4 Improving access to services for rural communities** Given that the paediatric patient population is relatively small and is spread over a wide geographic area, an integrated paediatric palliative care model will improve the management of services to clients. As previously discussed, the effective collaboration between providers, particularly for families living in rural or remote areas, where immediate access to and management by specialist staff is impractical, is essential if these families are to receive comprehensive and appropriate care.

Study findings: In our case study reviews and interviews undertaken with families we found that families living in rural and remote areas did not have the same access to services as those living in regional and metropolitan areas. For these families, regular telecommunication links with service providers were the main method of providing support. Many families living in rural areas stated that they experienced feelings of isolation because of the lack of local services. Some families also acknowledged that living in a rural area aggravated many of the problems they experienced with

accessibility, costs, travel, disruption of home life and so on. Palliative care agencies indicated there was also some difficulty in recruiting and training clinical and non-clinical service providers in rural or remote regions.

To address these problems, some agencies had developed specific strategies for providing additional support to these families through online community support services. However, in the main, community support services for families in need of paediatric palliative care require further development. This view is also supported by our literature review findings and the service improvement initiatives that have been undertaken in Australia and overseas.

- 5 **Improving the interfaces with other related sectors** Interfaces between paediatric palliative care and the disability and education sectors should be strengthened to ensure that a collaborative approach is adopted to achieving specified management and support goals.

Study findings: In our case study reviews we found that the degree to which a good working relationship between the palliative care service and the disability and education sectors existed was directly related to the level of resources available for service provision. We found that agencies with dedicated paediatric palliative care staff (particularly nurses and social workers) provided consultation and liaison services to the disability and education sectors. Other agencies indicated that adult and paediatric palliative care service providers should be integrated more effectively, and that this was not done adequately because of a shortage of resources. This view is also supported by our literature review findings and the service improvement initiatives that have been undertaken in Australia and overseas.

- 6 **Providing additional respite care** Respite services are viewed as an integral component of a best practice model for paediatric palliative care and are used to supplement home-based support services. Our review of the published literature has indicated that, while most families wish to spend as much time as possible at home, they also need access to respite care. They need several types of respite care to allow flexibility and choice, including short break respite, external respite facilities for children and adolescents, and emergency respite.

Study findings: In our case study reviews and family interviews we found that there were insufficient respite services to meet the needs of families with children who have life-threatening conditions. Additional respite services (both in-home and out-of-home respite) were highlighted as a key requirement, particularly for families caring for children with high degrees of disability and dependence. This view is also supported by our literature review findings and the service improvement initiatives that have been undertaken in Australia and overseas.

- 7 **Developing and implementing educational programs** In general, paediatricians determine if and when a child is referred to palliative care, and it is essential they understand what palliative care is and what it can offer families. In addition, paediatric health professionals are responsible for much of the early care of children with life-limiting conditions. Optimal care at this time includes helping children and families meet the challenges that may lie ahead. Best practice models facilitate this care, and ensure that the practice experience and research findings of workers in paediatric palliative care is fed back to the broader system. Formally designated educational programs are needed to provide such feedback and challenge the current practices of paediatric health professionals in their thinking about paediatric palliative care.

Study findings: Numerous provider agencies and families raised the issue of education in the area of paediatric palliative care during the study process. There were very few service providers who were trained in providing specialised paediatric palliative, end-of-life and bereavement care. There were

also limited educational opportunities in the area of paediatric palliative care. To compensate for this lack of training, some states were implementing training programs for both general and paediatric palliative care, especially for relevant professionals who may not come into contact with children in palliation on a regular basis.

We were advised that additional funding was required to provide paediatric palliative care training and education, particularly for staff in community-based agencies — as this area is developing into a specialty — and to meet the growing demand. To support the changes required to implement an integrated paediatric palliative care service model, additional resources are urgently needed for the education and training of staff involved in paediatric palliative care in community-based agencies. This view is also supported by our literature review findings and the service improvement initiatives that have been undertaken in Australia and overseas.

- 8 **Need to increase professional development** Health professionals in palliative care are not often required to provide care to children, so they need access to clinical support and professional development opportunities.

Study findings: Our review of case study sites showed that many agencies said it was important to increase the amount of professional development available to health professionals involved in providing paediatric palliative care. Staff need to understand the emotional reactions of children receiving palliative care and their families. However, this was generally not the case, as often home care staff were inexperienced and untrained in the care of dying children. Our family interviews indicated that, owing to a lack of formal staff development and exposure to paediatric palliative care, staff often had to rely on a trial and error approach to providing care.

Additional resources are required to provide staff development opportunities and thereby improve the quality and outcome of services provided by staff. This view is also supported by our literature review findings and the service improvement initiatives that have been undertaken in Australia and overseas.

- 9 **Evidence-based research to support clinical best practice** Paediatric palliative care is a largely unrecognised and underdeveloped area of care, and more research is needed to provide the evidence base for practice. The findings of our literature review and our consultations with service providers have shown that research into paediatric palliative care is lacking. Key areas where research is needed include:

- outcome measures,
- the epidemiology of life-limiting conditions,
- the cultural family dynamics and structures involved in the care and support process,
- the establishment of local registers of children with life-limiting conditions, and
- the spectrum of evidence on which to base clinical practice.

Study findings: Our review findings indicate that minimal research is being undertaken. While much research exists on the broad theme of parents and the death of a child, few studies seem to have focused on measuring performance or outcomes and developing improved models of care and service improvement initiatives. We believe it is important to provide adequate resources to enable the research essential to the development of a competent and confident workforce. This view is also supported by our literature review findings and the service improvement initiatives that have been undertaken in Australia and overseas.

- 10 **Establishing a family advocacy program** While there are relatively small numbers of children requiring paediatric palliative care, their need for services is significant. From this perspective, it is important that an effective advocacy program is available to ensure that the needs of patients are identified and addressed within the paediatric palliative care service delivery framework.

Study findings: During our review of case study sites, we found some agencies had developed a family advocacy program, however, these were in the minority. A number of agencies and families interviewed mentioned the need to develop and support the advocacy of families by strengthening the knowledge, role and influence of the family receiving paediatric palliative care. Family advocacy is directed towards building up and supporting families who have children with life-threatening conditions, and speaking up for opportunities, environments and lifestyles that are valued by, and available to, the majority of Australians. We believe that there are significant opportunities to improve the delivery of paediatric palliative care services in this area.

Chapter 8

Proposed strategies for improvement



This chapter outlines the strategies proposed for improving the delivery of paediatric palliative care services that have been supported by participants of the National Paediatric Palliative Care Workshop. This workshop was conducted to gain the views of stakeholders on our findings, our suggestions on opportunities for implementing improved paediatric palliative care models, and a range of other initiatives that we identified as useful during this review. The strategies are designed to address key components of evidence-based best practice paediatric palliative care models, with an emphasis on providing a comprehensive approach to service delivery that accords with the models.

1 Establishing a national paediatric palliative care reference group

Currently in Australia, each state is responsible for providing paediatric palliative care. For the most part, these services are provided under the auspices of each palliative care program except in those states (for example, Victoria and South Australia) where there has been a separate budget allocation and a strategic plan developed for providing these services. In order to elevate the profile of the needs of families who care for children with life-threatening conditions, we believe it is important to establish a national forum to develop national evidence-based definitions, standards and policies to address a range of issues affecting the delivery of paediatric palliative care.

Proposed strategy

We suggest that a national paediatric palliative care reference group (PPCRG) should be established. The identity of the auspicing agency for this group and its terms of reference requires further consideration. The purpose of this group would be to develop the evidence-based national definitions, standards and policies that are required to implement integrated paediatric palliative care models, including developing information, education and research strategies aimed at improving the delivery of paediatric palliative care.

This would provide an integrated national approach to changing the way these services are delivered, and would enable the best possible use to be made of research by ensuring that new evidence is used promptly and effectively to change health service delivery and care for children and families. An integrated national approach would help to avoid duplication of effort by states and provide a national focus for the major and most costly tasks of review and guideline development. It would ensure that the same accurate and timely information is provided to all stakeholder groups, including clinicians, consumers, policy makers and the media. It would also help to identify the priorities for improving paediatric palliative care services and to focus resources on these priorities.

The role of the PPCRG would also include:

- analysing research and making it readily available to families caring for children with life-threatening conditions, and health professionals;

- developing, disseminating and encouraging the adoption of clinical guidelines to improve the palliative, end-of-life and bereavement services for children and families;
- providing accurate and accessible information to families, primary care providers and other health professionals;
- developing a national monitoring system to provide information about all aspects of paediatric palliative care;
- determining which areas of paediatric palliative care require evaluation;
- considering collaborative projects focusing on service improvement;
- developing methods for analysing and interpreting data on service performance;
- developing high-level training and research strategies; and
- offering help and support to agencies seeking to conduct studies on any aspect of paediatric palliative care.

The philosophy and approach of the PPCRG would be guided by the following values:

- all aspects of its work would be based on the best available evidence;
- the views of consumers would inform the decision-making process;
- wherever possible, it would work in collaboration with a broad range of organisations concerned with supporting families caring for children with life-threatening conditions;
- it would use a multidisciplinary approach, bringing individuals with different expertise to work together;
- its work would be directed towards improving outcomes for children and families requiring palliative care services from the point of diagnosis through to bereavement; and
- it would adopt an innovative approach by seeking to better understand how best to improve care and developing approaches that may be adapted from other successful health service delivery initiatives.

Strengths and weaknesses

An assessment of the strengths and weaknesses of this strategy is summarised below.

Strengths	Weakness
<ul style="list-style-type: none"> • Provides a national focus for delivering paediatric palliative care. 	<ul style="list-style-type: none"> • Requires an investment of additional funding.
<ul style="list-style-type: none"> • May improve the responsiveness of the system as a whole to meeting the needs of clients and the population as a whole. 	
<ul style="list-style-type: none"> • Supports the pursuit of systematic development and improvement. 	
<ul style="list-style-type: none"> • Supports the undertaking of national and international research projects that will improve the quality of service delivery and outcomes. 	

Discussions at the National Paediatric Palliative Care Workshop confirmed that this was a desirable strategy to ensure future service improvements in paediatric palliative care.

2 Developing national clinical practice guidelines and protocols

Achieving the paradigm shift required to implement improved, integrated, family-centred paediatric models of care will require the collaboration of a range of stakeholders, including paediatric professionals, specialist children's hospitals, community-based health agencies, family advocacy groups, and government agencies. Such a collaboration could develop and implement clinical practice guidelines and procedures for palliative, end-of-life and bereavement care that meet the needs of children and families.

Proposed strategy

Workshop participants believed that the PPCRG should be responsible for developing and promulgating national guidelines and protocols to be implemented by agencies providing paediatric palliative care services. Developing and implementing these guidelines and protocols would support the provision of:

- comprehensive, timely and comprehensible information about diagnosis, prognosis, treatments and palliative care options for children;
- early and ongoing discussions about goals and preferences for care that will be maintained across the continuum of care (hospital, community and home);
- procedures that support the coordination and continuity of care and the timely flow of information within and across sites of care;
- effective and timely assessment, prevention and treatment of physical and psychological symptoms across the continuum of care; and
- compassionate and competent clinical management of end-of-life decisions.

Strengths and weaknesses

An assessment of the strengths and weaknesses of this strategy is summarised below.

Strengths	Weakness
<ul style="list-style-type: none">• Communicates clear national policies and guidelines that are founded on evidence-based best practice.	<ul style="list-style-type: none">• May require additional effort by service providers to ensure policies and protocols are implemented correctly.
<ul style="list-style-type: none">• May improve the responsiveness of the system as a whole to meeting the needs of clients and the population as a whole.	<ul style="list-style-type: none">• Would require additional training and education of service providers.
<ul style="list-style-type: none">• Supports the pursuit of systematic development and improvement.	<ul style="list-style-type: none">• Would require additional resources.

Discussions at the National Paediatric Palliative Care Workshop confirmed that this was a desirable strategy to ensure future service improvements in providing paediatric palliative care services. This strategy is also supported by a number of prominent international research studies (for example, Rollins 2002, Rushton and Catlin 2002), which have demonstrated that existing approaches to paediatric palliative care are inadequate in several important respects, and that national standards are required to ensure program improvements are achieved.

3 Improving the availability of information

It became evident during the project that there is limited access to information that would support families caring for children with life-threatening conditions and to service-related information on staffing, financial, activity and clinical indicators for paediatric palliative care. Comprehensive and timely information about both clinical and management aspects of paediatric palliative care is essential for many reasons, including:

- providing support to families (particularly in rural areas), local health care professionals, community hospitals and other relevant organisations through the internet, telemedicine and telephone consultative services;
- monitoring outcomes;
- improving service delivery; and
- undertaking research.

Proposed strategies

Achieving improvements in the availability of information requires the collaboration of a range of stakeholders, including paediatric professionals, specialist children's hospitals, community-based health agencies, family advocacy groups and government agencies. Such a collaboration could develop information programs and other resources to assist families and clinicians in local and rural areas on a statewide basis. The following strategies are proposed:

- 1 **Developing and implementing information packages** A range of information packages is required to support an integrated family-centred model of paediatric palliative care. Consultative services are required to advise general practitioners and local health care providers on all aspects of care for the child and family, from diagnosis through to bereavement. Guidelines and information resources are required on clinical and organisational issues to help families advocate for appropriate care to meet their needs. Resources are also required to support professional education and other programs that will help to ensure that palliative, end-of-life and bereavement care is coordinated across the continuum of care and across service providers.
- 2 **Developing a national paediatric palliative care database** In order to redress the lack of clinical and management information necessary to improve service delivery, it is important that consideration be given to developing (over the coming five years) a national paediatric palliative care information system for collecting and reporting data on the operation of paediatric palliative care services. Emphasis should be given to ensuring that clinical data are readily converted to information that is useful and accessible to clinicians. Further, systems should be implemented to ensure that financial and activity information essential to sound and responsive management of services is readily available to managers and policy makers.

Strengths and weaknesses

An assessment of the strengths and weaknesses of these strategies is summarised below.

Strengths	Weakness
<ul style="list-style-type: none">• Provides information to support families and service providers, and facilitates sound clinical and administrative decision making.	<ul style="list-style-type: none">• May reduce the time available to clinicians and managers to engage in aspects of their roles other than collecting and analysing data.
<ul style="list-style-type: none">• May improve the responsiveness of the system as a whole to the changing needs of individual clients and the population as a whole.	<ul style="list-style-type: none">• May not produce a discernible benefit for those required to collect the data despite investment in appropriate information systems.
<ul style="list-style-type: none">• Supports the pursuit of systematic service development and improvement.	<ul style="list-style-type: none">• May draw resources away from other priority areas to developing reporting systems.
<ul style="list-style-type: none">• Increases the capacity to identify and respond to deficiencies in the service system.	
<ul style="list-style-type: none">• Reduces the exposure of services, service providers and the system as a whole to unwarranted criticism.	
<ul style="list-style-type: none">• May help some groups or individuals to achieve their service-related objectives because of the availability of more timely, accurate information.	

Participants at the National Paediatric Palliative Care Workshop agreed that, while this strategy was desirable, implementing it would be a significant task. They felt that the PPCRG should give further consideration to the most efficient approach to both collecting and disseminating information, including to developing information packages and deciding which data collection elements are required to support clinical requirements for information reporting and monitoring client outcomes.

4 Increasing resource allocations

Our review of paediatric palliative care services across Australia is that, at present, there is insufficient funding to meet the needs of children with life-threatening conditions and their families. This has resulted in significant gaps in service in a range of areas, including home-based care and bereavement, sibling, psychosocial, respite and spiritual support. Additional funding is also required to support teaching, training and research programs.

The current allocation of resources appears to be based on historical allocations and, for many agencies, is imbedded in the global palliative care budget and in the capacity of groups or individuals to raise private contributions, which has been progressively decreasing. Some state health authorities (those of Victoria, New South Wales and South Australia) have allocated nominal funding to providing paediatric palliative care. However, service providers have advised that the level of funding is insufficient to meet increasing demand and the individual needs of clients.

Proposed strategies

The following strategies are proposed with respect to increasing the level of funding for paediatric palliative care:

- 1 the DHA considers adapting state health agreements to encourage the allocation of specific funding for providing paediatric palliative care services, and
- 2 individual state health jurisdictions consider allocating specific funding for providing paediatric palliative care services. Within this framework, consideration should be given to providing a rational and equitable basis for resource allocation, which recognises the need for integrated, statewide paediatric palliative care services, the increasing demand on services, and the level of unmet need.

Strengths and weaknesses

An assessment of the strengths and weaknesses of these strategies is summarised below.

Strengths	Weakness
<ul style="list-style-type: none"> • Provides additional funding to ensure a quality-based paediatric palliative care program across the continuum of care for families during palliation, death and bereavement. 	<ul style="list-style-type: none"> • May require movement of resources from the current allocations to commit additional resources to the paediatric palliative care program.
<ul style="list-style-type: none"> • Provides a more equitable approach to funding paediatric palliative care services. 	<ul style="list-style-type: none"> • Represents a significant challenge to budget holders of existing palliative care funds as there may be a need to reduce these funds to align resources with paediatric palliative care service provision.
<ul style="list-style-type: none"> • Provides the required level of resources to meet the needs of children, families and communities by providing interdisciplinary, holistic services, and supports the pursuit of systematic service development and improvement. 	<ul style="list-style-type: none"> • Places demands on government for resources to keep pace with service demand.
<ul style="list-style-type: none"> • Improves the accountability of paediatric palliative care service delivery, enabling the service costs to be reported, monitored and evaluated. 	

At the National Paediatric Palliative Care Workshop there was strong support for this strategy, and it was agreed that further discussions would have to be conducted with representatives of the Palliative Care Intergovernmental Forum, which comprises representatives from state health jurisdictions and Palliative Care Australia. The forum should consider the policy issues affecting the delivery of palliative care services in Australia and assess the best approach to implementing this strategy.

5 Designating funding for approved research projects

As previously discussed, our review of existing paediatric palliative care services in Australia has shown there are a number of significant gaps in meeting the needs of clients. Lacking are social supports for children and families, bereavement services, and emotional and spiritual support. We have also observed that there are significantly more resources available to children with malignant conditions than to those with non-malignant conditions, because the former receive more support from private fundraising. However, children with non-malignant conditions may live for many years with the accompanying physical, emotional and spiritual burdens of declining quality of life.

When children's lives end, their families need intense and long-term psychosocial and bereavement services. Currently, the psychosocial and bereavement resources, and support for health care professionals who care for these children, are minimal, because of the prevailing funding limitations.

To address these gaps, resources should be made available to support approved projects aimed at improving various aspects of paediatric palliative care. These projects could include clinical and behavioural research, and policy, organisational and educational initiatives.

Proposed strategies

The following strategies are proposed with respect to a number of key priority areas that should be addressed across Australia.

- 1 Developing protocols for bereavement support** As previously stated, a comprehensive bereavement program is required for families who have lost a child to a life-threatening condition. In this regard, we propose that the PPCRG considers the best strategy for developing national protocols and guidelines to enable:
 - the identification and coordination of culturally sensitive bereavement support services for parents and siblings,
 - the definition of bereavement support roles for hospital and community-based staff involved in providing paediatric palliative care services, and
 - the provision of appropriate debriefing programs in response to the bereavement needs and stresses of professionals who are assisting dying children and their families.
- 2 Developing culturally sensitive services** Our review of paediatric palliative care services has revealed that families from culturally and linguistically diverse backgrounds need culturally sensitive services. Our findings have shown that, while there is sometimes an assumption that the needs of families from such backgrounds are being met by resources in their own communities and they often do not ask for help, their needs are unmet and they struggle with little support (Beresford 1995).

The key barriers to providing services to this group of clients are:

- considerable time and funding resources are required to establish a relationship with different communities and to gain their trust;
- written materials have to be translated, media have to be specifically targeted and interpreters funded;

- the number of children requiring paediatric palliative care is very small, which complicates equity of access relative to the totality of needs in this area; and
- there is a lack of suitably trained multicultural staff.

We are proposing that funding be approved to undertake pilot projects focusing on key communities to develop culturally sensitive services that take into consideration issues of language, culture and spiritual beliefs.

- 3 **Respite care** As previously discussed, respite services are viewed as an integral component of a best practice model for paediatric palliative care and are used to supplement home-based support services. Our review has indicated that, while most families wish to spend as much time as possible at home, they also need access to respite care.

Several types of respite care are required to allow flexibility and family choice:

- short-term break care, over a number of hours or part of a day, provided by nurses or others trained in symptom management;
- external respite facilities that include nursing and symptom management for periods of several days, a week or more or at regular intervals, and that also include options both for family accommodation and respite without the family;
- emergency respite when a crisis occurs at home; and
- external respite facilities specifically for those in their mid to late teens, and young adults.

States and territories should consider providing additional respite services, particularly for families caring for children with high degrees of disability and dependence, as this was highlighted as a pressing need by services at all the case study sites. It should include the option for both in-home and out-of-home respite.

Strengths and weaknesses

An assessment of the strengths and weaknesses of these strategies is summarised below.

Strengths	Weakness
<ul style="list-style-type: none"> • Demonstrates a commitment to reducing the gaps in paediatric palliative care service delivery that have been identified in Australia and internationally. 	<ul style="list-style-type: none"> • Represents a significant resourcing challenge for both federal and state health jurisdictions.
<ul style="list-style-type: none"> • Provides an opportunity to undertake pilot projects in priority areas and then use the results across Australia. 	<ul style="list-style-type: none"> • Requires the support of key stakeholders both within and outside the paediatric palliative care system.
<ul style="list-style-type: none"> • Eliminates duplication of effort and resources as the emphasis is on sharing of knowledge and expertise. 	<ul style="list-style-type: none"> • May result in disruption to those in need of assistance if not pursued sensitively and systematically.
<ul style="list-style-type: none"> • Increases access to services. 	<ul style="list-style-type: none"> • May require additional resources to support realignment in the short term.
<ul style="list-style-type: none"> • Establishes an explicit direction for service development over a specified term. 	<ul style="list-style-type: none"> • Challenges groups that have effectively pursued their interests in the past.

The National Paediatric Palliative Care Workshop considered this to be a desirable strategy that would produce the needed service improvements in the future. It was considered that the PPCRG should give priority to establishing and conducting these research projects.

6 Educating and training staff

Our review findings have shown that few health care professionals are trained in providing specialised palliative, end-of-life and bereavement care to children and their families. These findings have also been supported by a number of international studies in which the importance of educating staff about caring for dying children and their families has been highlighted. Ashby and colleagues (1991) discussed the need for staff to understand the emotional reactions of children receiving palliative care, and those of their families. As previously discussed in this report, other researchers (Darbyshire, Haller and Flemings 1997 and Contro et al 2002 in particular) stated that often home care staff were inexperienced and untrained in the care of dying children. Hilden and colleagues (2001) found that paediatric oncologists reported a lack of education in paediatric palliative care and relied on 'trial and error' when making treatment decisions.

In our national review of paediatric palliative care service, the issue of education and training in the area was raised by stakeholders on numerous occasions. While it has been acknowledged that providing education programs alone would not guarantee changes in attitudes or behaviours, they would provide the essential basis of knowledge, skills and ethical understanding for all service providers involved in providing paediatric palliative care. These changes to the existing generalist, paediatric and specialist education curricula would contribute to the ongoing acceptance of paediatric palliative care as a defined and accepted area of teaching, research and patient care expertise. Currently, in Australia, there are only three paediatric palliative care specialists and more are needed to ensure sustained support for service improvement.

We understand that, in Australia, there was only one paediatric palliative care post-basic program available for nurses, at Flinders University in South Australia. We were also advised that there were limited educational opportunities for others working in paediatric palliative care. To compensate for this lack of training, a number of states had implemented training programs, both general and child specific, to provide training for other professionals who may not come into contact with children in palliation on a regular basis. Additional funding is required to provide paediatric palliative care training and education, particularly for staff in community-based agencies, as that area is developing into a specialty, and to meet the growing demand.

To support the change to an integrated paediatric palliative care service model, additional resources are urgently required for educating and training staff involved in providing paediatric palliative care in community-based agencies. Paediatric palliative care should evolve as a defined and accepted area of teaching, research and patient care expertise. In Australia, a very small group of paediatric palliative care specialists has taken on the role of providing consultative advice to service advisers, however, more specialists are needed across Australia to support improvements.

Proposed strategies

The following strategies for improving the education and training of staff involved in providing paediatric palliative care are proposed:

- introducing paediatric palliative care modules at a tertiary level within the appropriate health professions to give all health care professionals who work with children and families basic competence in palliative, end-of-life and bereavement care;

- identifying staff in the acute and palliative care sectors interested in paediatric palliative care who are willing to participate and take a leadership role in the field;
- providing specific funding to agencies for training and education purposes, including for the further development of state programs;
- establishing a group of paediatric palliative care specialists, under the auspices of the PPCRG, to take responsibility for acting as clinical role models, educating other professionals, and conducting research that extends the knowledge base for palliative, end-of-life and bereavement care;
- allocating sufficient resources to develop and implement innovative training programs in paediatric palliative care in the schools of medicine, nursing, social work, psychology and pastoral care, including setting minimum standards for program content and competency-based testing;
- providing paediatric residency and subspecialty fellowship programs that incorporate paediatric palliative care information;
- providing paediatric palliative care fellowships and similar training opportunities;
- providing training in paediatric palliative care for volunteers and other non-professional caregivers so that they can give care competently, particularly in the end-of-life stage;
- providing training for counsellors, psychologists and teachers to effectively accommodate the needs of terminally ill children and their classmates; and
- developing strategies aimed at evaluating selected techniques for educating health professionals in palliative, end-of-life and bereavement care.

Strengths and weaknesses

An assessment of the strengths and weaknesses of these strategies is summarised below.

Strengths	Weakness
<ul style="list-style-type: none"> • Provides an increased knowledge base for health professionals providing paediatric palliative care services. 	<ul style="list-style-type: none"> • Requires the allocation of additional resources for implementing training programs in schools of medicine, nursing and social work, including for the development of minimum standards for program content and competency-based testing.
<ul style="list-style-type: none"> • Improves awareness and education in the community and within the medical profession about the role of paediatric palliative care, to obtain earlier referrals and to improve understanding and communication. 	<ul style="list-style-type: none"> • Requires the support of key stakeholders both within and outside the paediatric palliative care system.
<ul style="list-style-type: none"> • Improves quality and outcomes of services for families and service providers. 	

The National Paediatric Palliative Care Workshop strongly supported this strategy, as effective education and training of staff in the care of dying children and their families is a vital component of good paediatric palliative care. It is proposed that the PPCRG, together with representatives of the Palliative Care Intergovernmental Forum, develop strategies for implementing a range of initiatives that will improve the education and training of health professionals and other support staff in family-centred service delivery.

7 Developing performance measurement mechanisms

Ongoing nationally agreed performance measurement mechanisms are required — clinical indicators based on evidence-based best practice. Currently, in Australia, performance measurement is largely focused on undertaking consumer satisfaction surveys and reviewing the practice of a service in the management of a condition, analysis of the results, and then altering practice to take into account adverse findings or omissions. The main thrust has been to assess the evidence for the benefit of a treatment, so that changes could be made to enhance the current practice. In chapter 3, we said that Palliative Care Australia had developed a series of performance indicators for palliative care, many of which are useful to individual programs and could have some applicability to paediatric palliative care. Our review of the literature in this area has shown there is now a shift in emphasis to clinical governance rather than effectiveness, which is more an assessment of competence than of palliative care management.

Proposed strategy

To implement improvements in paediatric palliative care services, current practice must be examined with regard to unacceptable variations in treatment, as well as clinical and cost-effectiveness. Reviews of paediatric palliative care programs must be undertaken that will help to identify any serious or persistent clinical problems. In this regard, we believe there is a role for the PPCRG: to build on the work that has been done in Australia and overseas by developing a national standard for performance measurement that is in accordance with evidence-based best practice.

Strengths and weaknesses

An assessment of the strengths and weaknesses of this strategy is summarised below.

Strengths	Weakness
<ul style="list-style-type: none">• Provides an increased knowledge base on which to base measurements of the quality of outcomes.	<ul style="list-style-type: none">• Requires the allocation of additional resources to enable the development and implementation of national indicators for measuring performance and outcomes.
<ul style="list-style-type: none">• Improves the accountability of service providers and provides an understanding of the effectiveness of service delivery approaches.	<ul style="list-style-type: none">• Requires the commitment and support of key stakeholders within the paediatric palliative care system.
<ul style="list-style-type: none">• Improves quality and outcomes of services for both families and service providers.	

At the National Paediatric Palliative Care Workshop there was agreement that developing national performance indicators for paediatric palliative care was an integral part of delivering an integrated and holistic family-centred service. This strategy is also supported by international research studies.

8 Evaluating service improvement strategies

Program evaluation is an essential organisational practice within the health sector. However, it is not practised consistently across program areas, nor is it sufficiently well integrated into the day-to-day management of most programs. Program evaluation will also be necessary for fulfilling the PPCRG's operating principles with respect to future decision making, and to ensure the strategies that have been developed and implemented have performed effectively and achieved the desired outcomes.

These operating principles imply that there are several ways to improve the planning and management of service improvement strategies. They underscore the need for clear plans, inclusive collaborations and feedback systems that allow learning and ongoing improvement to occur. One way to ensure that these strategies honour the PPCRG’s principles is to ask paediatric palliative care programs to conduct routine, practical evaluations that provide information for management and improve program effectiveness.

Proposed strategy

In order to ensure that the national paediatric palliative care program remains relevant and that there is progress in implementing the agreed service improvement strategies, progress has to be monitored. A key focus of the paediatric palliative care work plan would be a broad framework established by the PPCRG within which the impact of the projects to be undertaken could be evaluated. This will facilitate the implementation and evaluation of specific best practice service improvement strategies.

The framework for the paediatric palliative care program evaluation should be designed to assess the strategies implemented against a set of specific aims and a number of basic hypotheses, such as:

- the strategy will help improve quality of life for children with life-threatening conditions;
- the strategy will help to facilitate improvements in awareness and understanding about the benefits of paediatric palliative care, as well as improving communication and collaboration between health professionals, other support staff and children with life-threatening conditions and their families; and
- the strategy will result in a more appropriate use of health services.

In broad terms, we see evaluation as including the following components.

Type of evaluation	Purpose
Implementation or process evaluation	<ul style="list-style-type: none"> • To assess the establishment, operation and management of the project/s against key objectives.
Outcome evaluation	<ul style="list-style-type: none"> • To measure the benefits to recipients according to their identified need and other key outputs of the project/s.
Program impact evaluation	<ul style="list-style-type: none"> • To examine the overall impact of the project/s on the needs of the target group, including how their quality of life is affected. • To assess the appropriateness of the program. • To examine the cause-effect link between inputs, strategies and outputs. • To suggest directions, management options and sponsorship issues for such programs.
Efficiency evaluation	<ul style="list-style-type: none"> • To determine the extent to which the program outcomes are achieved at a reasonable cost and in a reasonable time.

Strengths and weaknesses

An assessment of the strengths and weaknesses of this strategy are summarised below:

Strengths	Weakness
<ul style="list-style-type: none">• Provides a framework for evaluating work program.	<ul style="list-style-type: none">• Evaluation may be perceived as a low priority for resourcing by some.
<ul style="list-style-type: none">• Represents an opportunity to establish sound arguments about progress and the direction being pursued nationally.	<ul style="list-style-type: none">• Evaluation of the work plans will require sustained activity, particularly to establish baseline and outcome measures.
<ul style="list-style-type: none">• Establishes a framework in which clear expectations of the overall service system can be developed.	
<ul style="list-style-type: none">• Contributes to developing an information base to support the creation of future strategies.	
<ul style="list-style-type: none">• Supports communication of the direction being pursued to all stakeholders.	

The National Paediatric Palliative Care Workshop agreed that all service improvement initiatives should be evaluated after they are implemented. This strategy is also supported by international research studies.

Conclusion

This chapter has sought to put forward reinforcing strategies to address the multidimensional problems affecting the provision of paediatric palliative care services in Australia. They include proposals for integrated structural reform, changing resource allocation, improving the quality of services by conducting evidence-based research projects into social supports for children and families, educating and training staff, and evaluating programs. We believe this report will present many challenges to the Australian health sector, and requires an ongoing collaborative effort between national and state governments, individual service providers and the families who care for children with life-threatening conditions to systematically improve palliative care services.

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Appendix A



Palliative Care Survey Form

PALLIATIVE CARE SURVEY FORM

AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH AND AGEING

National Survey of Paediatric Palliative Care Service Providers

This survey is being conducted with all Palliative Care service providers across Australia to gain an understanding of the range and type of paediatric palliative care services provided. The following instructions relate to the completion of the survey form.

Instructions for completion of the survey

- a) The Survey Form should be completed for each Palliative Care service provider. The principal objective is to identify those organisations who provide paediatric palliative care to clients. For the purposes of this survey, paediatric palliative care clients include children aged between 0 to 18 years.
- b) Data for this survey relates to the 2001/2002 financial year.
- c) Please refer to the associated Survey Guidelines for information on how to complete this form and definitions of data items.

Check list on completion of the survey form

After you have completed answering the survey form, please check that you have done the following:

Please check that:

- all questions have been answered.
- Question 1
 - if you answered “Yes”, that all the questions in the survey have been completed.
 - if you answered “No”, that no further questions have been answered.
- Question 11
 - if you provided the expenditure related to paediatric palliative care service provision, that you continued answering Questions 13 onwards.
 - if you were unable to provide the expenditure related to paediatric palliative care service provision, that you answered Questions 12 onwards.
- Completed survey forms are to be returned to HMA by Friday 30th August 2002 (refer to section 2.2 of survey guidelines).

THANK YOU FOR COMPLETING THE SURVEY FORM

Please contact the Project Manager, Lilian Lazarevic (08) 8150-5555
should you require any assistance.

AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH AND AGEING

Survey of Paediatric Palliative Care Services

This survey is being conducted to gain an understanding of the range and type of paediatric palliative care services provided across Australia. One form should be completed for each service provider and relates to services provided to clients (children aged between 0 to 18 years) during the financial year 2001/2002. Please refer to the associated Survey Guidelines for information on how to complete this form and definitions of data items.

NAME OF ORGANISATION: _____

NAME OF THE PERSON COMPLETING THE FORM: _____

TELEPHONE NUMBER: _____

FAX NUMBER: _____

EMAIL ADDRESS: _____

1. DOES YOUR ORGANISATION PROVIDE PAEDIATRIC PALLIATIVE CARE SERVICES?

(Tick the relevant box)

01. Yes

02. No

If you answered "No", thank you for completing the survey

If you answered "Yes" please answer the following questions

2. POST CODE OF PRINCIPAL SERVICE LOCATION (Enter relevant code) |_|_|_|_|_|

3. IDENTIFY THE CATCHMENT AREA OF PAEDIATRIC PALLIATIVE CARE SERVICES

(Tick the relevant box)

01. Local

02. Regional

03. Statewide

04. Other (Please Specify) _____

4. WHAT ARE THE HOURS OF SERVICE OPERATION FUNDED? (Tick relevant box)

01. Business hours 5 days a week

02. Business hours 6 days a week

03. Business hours 7 days a week

04. 24 hour service

05. Other (Please Specify) _____

5. IS YOUR SERVICE HOSPITAL OR COMMUNITY BASED? (Tick relevant box)
- 01. Hospital
 - 02. Community
 - 03. Hospital and community
 - 04. Other (Please Specify)

01. Total number of paediatric palliative care clients serviced 2001/2002 |__|__|__|

02. Total number of private paediatric palliative care clients serviced during 2001/2002 |__|__|__|

|__|__| _____

6. WHAT TYPES OF PAEDIATRIC PALLIATIVE CARE SERVICES ARE PROVIDED BY YOUR AGENCY? (Tick the relevant boxes)

- 01. Bereavement Care
- 02. Respite
- 03. Hospice
- 04. Community-based services
- 05. Hospital-based services
- 06. Case management
- 07. Hospital-based outreach services
- 08. Family support services
- 09. Sibling support services
- 10. Adjuvant therapy
- 11. Symptom control
- 12. Emotional support
- 13. Information
- 14. Volunteer support services
- 15. Community liaison
- 16. Other (Please Specify) _____

7. TOTAL NUMBER OF PALLIATIVE CARE CLIENTS REGISTERED DURING 2001/2002?

(Include only palliative care clients who received services during 2001/2002) |__|__|__|

8. TOTAL PAEDIATRIC PALLIATIVE CARE CLIENTS REGISTERED DURING 2001/2002? (Include only paediatric palliative care clients who received services during 2001/2002)

9. NUMBER OF CLIENTS REGISTERED WITH THE FOLLOWING CONDITIONS DURING 2001/2002?

- 01. Failed curative treatment (eg cancers) |__|__|__|
- 02. Treatment to prolong life (eg cystic fibrosis) |__|__|__|
- 03. Progressive diseases (eg Batten disease) |__|__|__|
- 04. Severe neurological conditions (eg cerebral palsy) |__|__|__|
- Other conditions, where patients are undergoing continuing curative treatment |__|__|__|

10. WHAT WAS THE TOTAL EXPENDITURE FOR PALLIATIVE CARE SERVICES (INCLUDING PAEDIATRIC PALLIATIVE CARE) DURING 2001/2002? (Identify the total expenditure rounded up to the nearest dollar)

\$|__|__|__|__|__|__|__|__|__|

11. WHAT WAS THE EXPENDITURE FOR PROVIDING PAEDIATRIC PALLIATIVE CARE SERVICES DURING 2001/2002? (Identify the total expenditure rounded up to the nearest dollar)

\$|__|__|__|__|__|__|__|__|__|

12. IF UNABLE TO ANSWER Q11, PLEASE PROVIDE ESTIMATE OF THE PROPORTION OF EXPENDITURE THAT WOULD BE RELATED TO PAEDIATRIC PALLIATIVE CARE (Estimate the percentage of total palliative care services that relate to paediatric palliative care eg 60%)

|__|__|__|__|%

13. ESTIMATE THE PROPORTION OF DIRECT AND INDIRECT EXPENDITURE DURING 2001/2002. (Total of direct and indirect to add to 100%)

- 01. Failed curative treatment (eg cancers) |__|__|__|%
- 02. Treatment to prolong life (eg cystic fibrosis) |__|__|__|%
- 03. Progressive diseases (eg Batten disease) |__|__|__|%
- 04. Severe neurological conditions (eg cerebral palsy) |__|__|__|%
- 05. Other conditions where patients are undergoing continuing curative treatment |__|__|__|%

Proportion of Indirect Expenditure (not client related)

06.	Liaison with service providers	_ _ %
07.	Staff support	_ _ %
08.	Staff education	_ _ %
09.	Research	_ _ %
10.	Fund Raising	_ _ %
11.	Other (Please specify)	_ _ %
	_ _ _____	

14. IDENTIFY THE PROPORTION OF RESOURCES USED IN PROVIDING PAEDIATRIC PALLIATIVE CARE SERVICES DURING 2001/2002 (Total to add to 100%)

01.	Bereavement Care	_ _ %
02.	Respite	_ _ %
03.	Hospice	_ _ %
04.	Community-based services	_ _ %
05.	Hospital-based outreach	_ _ %
06.	Case management	_ _ %
07.	Family support services	_ _ %
08.	Sibling support services	_ _ %
09.	Adjuvant therapy	_ _ %
10.	Symptom control	_ _ %
11.	Emotional support	_ _ %
12.	Information provision	_ _ %
13.	Community liaison	_ _ %
14.	Other	_ _ %

15. NUMBER OF STAFF EMPLOYED BY YOUR SERVICE (Identify the number of staff (FTEs eg 1.5 nurses) that were employed by your service on 30 June 2002)

01.	Paediatric Oncologist	_ _ . _
02.	Palliative Physician	_ _ . _
03.	Pain Management Specialist	_ _ . _
04.	Paediatrician	_ _ . _
05.	Oncologist	_ _ . _
06.	GP	_ _ . _
07.	Paediatric Palliative Nurse	_ _ . _
08.	Registered Nurse	_ _ . _
09.	Social Workers	_ _ . _
10.	Chaplains	_ _ . _
11.	Pastoral care workers	_ _ . _
12.	Physiotherapists	_ _ . _
13.	Occupational therapists	_ _ . _
14.	Psychologist	_ _ . _
15.	Mental health workers	_ _ . _
16.	Other Allied Health Staff	_ _ . _
17.	Administrative Staff	_ _ . _
18.	Other Staff	_ _ . _

16. WHAT OTHER CLINICAL SERVICES ARE YOU ABLE TO ACCESS IN PROVIDING PAEDIATRIC PALLIATIVE CARE TO CLIENTS? (Tick relevant services)

- 01. Paediatric Oncologist
- 02. Palliative Physician
- 03. Pain Management Specialist
- 04. Paediatrician
- 05. Oncologist
- 06. GP
- 07. Paediatric Palliative Nurse
- 08. Registered Nurse
- 09. Social Workers
- 10. Physiotherapists
- 11. Occupational therapists
- 12. Psychologist
- 13. Mental health workers
- 14. Other Allied Health Staff

17. WHAT WERE THE ESTIMATED TOTAL NUMBER OF VOLUNTEER HOURS USED IN PROVIDING NON CLINICAL SUPPORT TO PAEDIATRIC PALLIATIVE CARE CLIENTS DURING 2001/2002? (Estimate total volunteer hours provided during 2001/2002)

|_|_|_|_|_|_|_|_|_|hrs

18. IS YOUR AGENCY ABLE TO MEET ALL THE NEEDS OF PAEDIATRIC PALLIATIVE CLIENTS? (Tick relevant box)

- 01. Unable to meet client needs
- 02. Partially able to meet client needs
- 03. Able to meet all client needs

19. IF YOU ARE UNABLE TO MEET ALL THE NEEDS OF YOUR PAEDIATRIC PALLIATIVE CARE CLIENTS, PLEASE SPECIFY THE REASONS (eg unavailability of pain management specialists)

|_|_| 01. _____

|_|_| 02. _____

|_|_| 03. _____

(There is space allowed for three key reasons to be identified, with four lines of text available for each reason. If more room is needed, feel free to attach another sheet of paper.)

Appendix B



Survey Guidelines

Healthcare Management Advisors Pty Ltd
ACN 081 895 507
PO Box 10086 Gouger Street, Adelaide SA 5000
1st Floor, 65 Henley Beach Road, Mile End SA 5031
Phone (08) 8150-5555 Fax (08) 8150-5599

6 August 2002

Australian Government Department of Health and Ageing

Review of Paediatric Palliative Models of Care

SURVEY GUIDELINES

Table of Contents

Section	Page
INTRODUCTION	129
SURVEY PROCESS	130
DATA DEFINITIONS AND GUIDELINES	131

1 Introduction

Healthcare Management Advisors (HMA) have been engaged by the Australian Government Department of Health and Ageing to undertake a national review of Paediatric Palliative Models of Care. This project forms part of the National Strategy for Palliative Care. It represents the commitment of the Commonwealth, State and Territory governments, palliative care service providers and community based organisations to the development and implementation of palliative care policies, strategies and services that are consistent across Australia, and to the delivery of quality palliative care that is accessible to all people who are dying. In this context the project presents an important and timely opportunity to contribute the development of paediatric palliative care services in Australia. It will involve broad based consultation with health service planners and providers together with consumers of paediatric palliative care services in order to fully understand the current models of care that are in existence.

1.1 PROJECT AIMS

The aims of this project are to:

- review models of paediatric palliative care across different life limiting illnesses;
- identify which service models best meet the palliative care needs of dying children and their families; and
- identify potential areas for future development.

1.2 SURVEY OBJECTIVES

A key part of the project is to conduct a survey that is targeted at all paediatric palliative care service providers in Australia. For the purposes of this survey, paediatric palliative care clients are those who are aged between 0 to 18 years. This is a concise survey which will locate each service on a range of factors relating to organisational characteristics, approach to services, client groups targeted, community vs hospital based and so on.

The survey form will need to be completed by each service provider with respect to providing key service, activity and resource utilisation data (relating to clients aged 0 to 18 years) for the 2001/2002 financial year and returned to HMA by Friday 30th August 2002.

We are suggesting that the Palliative Care Coordinator (or a person who has a very good understanding of palliative care operations) in each organisation be responsible for completion of this survey form for return to HMA. Should you require further information to assist you to complete the survey form please the HMA Project Manager:

Lilian Lazarevic,
Project Manager
Healthcare Management Advisors
Telephone (08) 8150 5580 or Mobile 0419 839 877.

2 Survey Process

This section outlines the key tasks that relate to the persons completing the survey form. A full set of guidelines describing the survey process in detail is to be provided to each palliative care service provider.

2.1 PROCESS GUIDELINES

The survey form is to be completed by each organisation relating to services provided to clients registered with the palliative care service (and who have received a service) during the financial year 2001/2002.

If for any reason the survey form is spoiled, we have enclosed a number of additional copies. If further copies are required please ring the Project Manager who will arrange additional forms to be sent out to you.

Check list on completion of the survey form

After you have completed answering the survey form, please check that you have the logical sequencing of the form correct as follows:

- If you have answered “yes” to Question 1, all questions from 1 to 19 inclusive have been answered.
- If you have answered “no” to Question 1, no further questions have been answered.
- If you were not able to provide the 2001/2002 operating expenditure for Paediatric Palliative Care Services in Question 11, then answer Question 12.
- Respondents who were able to provide the 2001/2002 operating expenditure for Paediatric Palliative Care Services are required to go to Question 13.

2.2 RETURN OF SURVEY FORMS

Please return the survey form to the Lilian Lazarevic, Project Manager, Healthcare Management Advisors on or before Friday 30th August 2002 at the following address: She will be in touch with you on that day to see if you need assistance to achieve that deadline.

Lilian Lazarevic
Project Manager
Healthcare Management Advisors
PO Box 10086
Gouger Street
ADELAIDE SA 5000.

3 Data Definitions and Guidelines

This section provides comprehensive definitions for each of the questions asked on the survey form.

3.1 GUIDELINES FOR COMPLETION OF DATA ITEMS

Question 1. Does your organisation have a paediatric palliative care service?

Respondents are requested to identify if they provide paediatric palliative care services to clients by ticking the relevant box:

01. Yes

02. No

- If you have ticked no, then no further information is required, please return your form directly to HMA at the nominated address.
- If you have ticked yes, then please continue to answer questions 2 to 19 inclusive.

Question 2. Post code of Service Provider

Enter the post code of the organisation/agency providing the paediatric palliative care service.

Question 3. Catchment Area for Service Provision

The catchment area (or catchment population) refers to the geographic (or spread of population) over which paediatric palliative care services are provided. Please tick the relevant box:

01. Local

02. Regional

03. Statewide

04. Other (Please Specify) _____

Where another area is identified please specify the area.

Question 4. Hours of Service Operation

This question relates to the business hours of operation for which the paediatric palliative care service is funded. Please tick the relevant box:

- 01. Business hours 5 days a week
- 02. Business hours 6 days a week
- 03. Business hours 7 days a week
- 04. 24 hour service
- 05. Other (Please Specify)

|_|_| _____

Question 5. Hospital or Community based Service

Tick the relevant box which best describes your paediatric palliative care service eg Hospital, Community or a mix of Hospital and Community. Definitions of these service types are provided below:

Code	Type of Service	Definition
01	Hospital based services	<ul style="list-style-type: none">• Paediatric palliative care services that are provided within the hospital setting only (eg provision of multi disciplinary care to clients in the hospital including inpatient and outpatient services).
02	Community based services	<ul style="list-style-type: none">• Paediatric palliative care services that are provided in the community setting only (eg home based nursing).
03	Hospital and community based services	<ul style="list-style-type: none">• Paediatric palliative care services that are provided both in the hospital and community sectors.
04	Other (please specify)	<ul style="list-style-type: none">• Identify the hours of operation for providing paediatric palliative care services.

Question 6. Types of Paediatric Palliative Care Services Provided

Respondents are requested to tick the types of paediatric palliative care services that are provided to registered clients as follows:

Code	Type of Service	Definition
01	Bereavement Care	<ul style="list-style-type: none">Includes activities which are undertaken by health professionals to assist and support families in dealing with the grief caused as a result of the loss of a child. Bereavement care focuses on non-physical care given to clients that aims to address psychological and/or social client needs during this period.
02	Respite	<ul style="list-style-type: none">Respite care (short-term admission, usually in order to give a carer respite from the provision of care.
03	Hospice	<ul style="list-style-type: none">Hospice is an establishment providing paediatric palliative care to terminally ill patients.
04	Community based services	<ul style="list-style-type: none">Services provided to clients in the community setting (eg domiciliary nursing services) or support services to other establishments.
05	Hospital based services	<ul style="list-style-type: none">Services provided in a specialised facility dedicated to the provision of acute care services for paediatric palliative care patients.
06	Case Management	<ul style="list-style-type: none">Case management involves a proactive approach to planning and coordination of care based on client needs across the continuum involving acute and community-based resources and other services providers.
07	Hospital based outreach services	<ul style="list-style-type: none">Hospital based outreach services are events related to treatment of patients by hospital staff in a location that is not part of the hospital campus (such as in the patient's home).
08	Family Support Services	<ul style="list-style-type: none">The provision of a range of emotional, social, and spiritual support for child, parents, siblings and other relatives and school mates.
09	Sibling Support Services	<ul style="list-style-type: none">The provision of specific services to support siblings including emotional, social and spiritual support.
10	Adjuvant therapy	<ul style="list-style-type: none">Adjuvant therapy is defined as the use of another form of treatment in addition to and following the initial curative procedure or treatment (eg the provision of chemotherapy and radiotherapy services).

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| 11 | Symptom control | <ul style="list-style-type: none"> • Refers to the provision of services to control distressing symptoms the provision of appropriate medical and nursing expertise 24 hours a day. |
| 12 | Emotional support | <ul style="list-style-type: none"> • Focuses on non-physical care given to a client, which aims to address the affective, psychological and/or social needs (eg well being, decision-making support and values-clarification). |
| 13 | Information | <ul style="list-style-type: none"> • Refers to providing information and/or instruction about a specific body of knowledge and/or procedure, which is relevant to the person's situation (eg provision of information relating to disease process, technical procedure, health maintenance, health promotion and techniques for coping with life limiting illnesses). |
| 14 | Volunteer Support Services | <ul style="list-style-type: none"> • Non-clinical services provided to clients on a volunteer basis. |
| 15 | Community liaison | <ul style="list-style-type: none"> • Activities involved in promoting paediatric palliative care within the community. |
| 16 | Other (please specify) | <ul style="list-style-type: none"> • Please specify any other paediatric palliative care service that is provided by your organisation to registered clients. |

Question 7. Total Number of Palliative Care Clients Registered

Identify the total number of palliative care clients that were registered with your organisation and who received services during 2001/2002. Please note this figure is to include both adult and paediatric palliative care clients.

Question 8. Total Number of Paediatric Palliative Care Clients that received services

This question requires the following information:

- Identify the total number of paediatric palliative care clients that were registered with your organisation and received services during 2001/2002.
- Identify the total number of clients who were private.

Question 9. Number of Clients Registered with the following conditions

This question seeks to identify the numbers of clients that were registered with the organisation/agency and received services during 2001/2002 in accordance with the following patient categories:

Code	Type of Service	Definition
01	Failed curative treatment conditions	<ul style="list-style-type: none">• Conditions for which curative treatments have failed, such as cancers
02	Treatment to prolong life	<ul style="list-style-type: none">• Conditions for which intensive treatment may prolong and enhance life, but premature death still occurs, such as cystic fibrosis
03	Progressive diseases	<ul style="list-style-type: none">• Progressive diseases for which treatment is exclusively palliative, but may extend over many years, such as Batten disease
04	Severe neurological conditions	<ul style="list-style-type: none">• Conditions where severe neurological conditions, though not progressive, lead to vulnerability and increased susceptibility to complications and premature death, such as severe cerebral palsy
05	Other conditions, where a patient is undergoing continuing curative treatment	<ul style="list-style-type: none">• Other conditions where patients are undergoing continuing curative treatment

Question 10. Total Expenditure incurred in providing Palliative Care Services

Respondents are requested to provide the total expenditure (rounded to the nearest dollar) related to the provision of Palliative Care Services for the 2001/2002 financial year. Please note the expenditure relating to the provision of paediatric palliative care is to be included in this amount).

Question 11. Total Expenditure incurred in providing Paediatric Palliative Care Services

Respondents are requested to provide the total expenditure (rounded to the nearest dollar) related to the provision of Paediatric Palliative Care services for the 2001/2002 financial year.

Please note that if the expenditure is not known go to Question 12.

Question 12. Estimate the Proportion of expenditure that is related to providing Paediatric Palliative Care services.

For those respondents who were unable to answer Question 11, please estimate the proportion of expenditure (expressed as a percentage) that were related to the provision of Paediatric Palliative Care Services during 2001/2002.

Question 13. Proportion of direct and indirect expenditure for provision of paediatric palliative care services during 2001/2002.

This question identifies both direct (client related) and indirect (not client related) expenditure associated with providing paediatric palliative care services during 2001/2002. You are requested to estimate the proportion of expenditure for direct and indirect services.

- Using the five (5) client groups described in Question 9 above, respondents are requested to estimate the proportion of total expenditure spent (expressed as a percentage) on the delivery of paediatric palliative care services during 2001/2002.
- In addition, respondents are requested to provide an estimate of the proportion of expenditure (expressed as a percentage) on the following indirect patient related activities undertaken during 2001/2002:

Code	Type of Service	Definition
01	Failed curative treatment	<ul style="list-style-type: none"> • Estimate the proportion of expenditure related to the provision of services to clients where curative treatment has failed.
02	Treatment to prolong life	<ul style="list-style-type: none"> • Estimate the proportion of expenditure related to the provision of services to clients where treatment to prolong life is being undertaken.
03	Progressive diseases	<ul style="list-style-type: none"> • Estimate the proportion of expenditure related to the provision of services to clients who have progressive diseases.
04	Severe neurological conditions	<ul style="list-style-type: none"> • Estimate the proportion of expenditure related to the provision of services to clients with severe neurological conditions.
05	Other conditions where patient is undergoing continuing curative treatment	<ul style="list-style-type: none"> • Estimate the proportion of expenditure related to the provision of services to clients who are undergoing continuing curative treatment.
07	Liaison with service providers	<ul style="list-style-type: none"> • Provision of advice and assistance to community based service providers (eg GPs) and other community agencies.
08	Staff support	<p>Staff support activities include:</p> <ul style="list-style-type: none"> • access to a psychologist for staff experiencing difficulties; • provision of individual counselling and debriefing sessions; • availability of a peer support program to support staff in coping with work, personal related issues and to increase the awareness of acute and chronic stressors within the work environment.
09	Staff education	<p>Staff education activities include:</p> <ul style="list-style-type: none"> • Conduct of staff training seminars on such issues as grief and life threatening disorders. • Conduct of specific professional development activities for relevant staff regarding principles of palliative care and bereavement care etc).

- | | | |
|----|------------------------|---|
| 10 | Research | • Participation in paediatric palliative care research projects |
| 11 | Other (please specify) | • Please identify any other indirect patient related activities that are undertaken by your organisation. |

Please note the total of percentage estimates for both direct and indirect expenditure must add to 100%

Question 14. Estimate the Proportion of resources used in providing Paediatric Palliative Care Services during 2001/2002.

Respondents are requested to provide an estimate of the resources used during 2001/2002 (expressed as a percentage) associated with the provision of the types of services as follows:

- | | | |
|-----|--------------------------|-------|
| 01. | Bereavement Care | _ _ % |
| 02. | Respite | _ _ % |
| 03. | Hospice | _ _ % |
| 04. | Community-based services | _ _ % |
| 05. | Hospital-based outreach | _ _ % |
| 06. | Case management | _ _ % |
| 07. | Family support services | _ _ % |
| 08. | Sibling support services | _ _ % |
| 09. | Adjuvant therapy | _ _ % |
| 10. | Symptom control | _ _ % |
| 11. | Emotional support | _ _ % |
| 12. | Information provision | _ _ % |
| 13. | Community liaison | _ _ % |
| 14. | Other | _ _ % |

Question 15. Number of Staff employed by your service as at 30 June 2002.

Please identify the relevant full time equivalent (FTE eg 1.5) ratios for all staff that were employed by your organisation in providing palliative care services as at 30th June 2002 in accordance with the following employee classifications:

01. Paediatric Oncologist	_ _ · _
02. Palliative Physician	_ _ · _
03. Pain Management Specialist	_ _ · _
04. Paediatrician	_ _ · _
05. Oncologist	_ _ · _
06. GP	_ _ · _
07. Paediatric Palliative Nurse	_ _ · _
08. Registered Nurse	_ _ · _
09. Social Workers	_ _ · _
10. Chaplains	_ _ · _
11. Pastoral care workers	_ _ · _
12. Physiotherapists	_ _ · _
13. Occupational therapists	_ _ · _
14. Psychologist	_ _ · _
15. Mental health workers	_ _ · _
16. Other Allied Health Staff	_ _ · _
17. Administrative Staff	_ _ · _
18. Other Staff	_ _ · _

Question 16. Other clinical services able to be accessed

This question seeks to identify other clinical services that are available to paediatric palliative care clients. Please tick the relevant consulting services available:

- 01. Paediatric Oncologist
- 02. Palliative Physician
- 03. Pain Management Specialist
- 04. Paediatrician
- 05. Oncologist
- 06. GP
- 07. Paediatric Palliative Nurse
- 08. Registered Nurse
- 09. Social Workers
- 10. Physiotherapists
- 11. Occupational therapists
- 12. Psychologist
- 13. Mental health workers
- 14. Other Allied Health Staff

Question 17. Estimated number of volunteer hours

Respondents are requested to estimate the total number of volunteer hours used during 2001/2002 in providing non clinical paediatric palliative care support services to clients. The types of volunteer activity to be included are:

- Support for families; and
- Indirect support of agency work, such as fund raising activities.

Question 18. Able to meet all needs of clients

Respondents are requested to tick the relevant box to indicate the degree to which their agency is able to meet the needs of paediatric palliative care clients as follows.

- 01. Unable to meet client needs
- 02. Partially able to meet client needs
- 03. Able to meet all client needs

Question 19. Reasons why needs of clients are not being met

If the agency is not able to meet certain needs of paediatric palliative care clients, respondents are asked to specify the specific reasons. Please specify the key reasons for unmet need:

|_|_|01 _____

|_|_|02 _____

|_|_|03 _____

There is space allowed for three key reasons to be identified, with four lines of text available for each reason. If more room is needed, please feel free to attach another sheet of paper.

Appendix B



Appendix C Interview participants*

Interview participant(s)	Child's age at diagnosis	Child's age at death	Diagnosis
Mother and daughter	13 years old	15 years	Cancer
Mother (Interview not transcribed due to technical difficulties)	?	17 years	Cancer
Mother	2 years old	4 years	Cancer
Mother and father	3 years old	5 years	Cancer
Mother and father	13 years old (approx)	15 years	Cancer
Mother and father	10 days old	2 years	Congenital abnormality and neurodegenerative disorder
Aunt and carer at time of child's death	14 years old	16 years	Cancer
Mother and father	13 days old	9 months	Gastrointestinal infection and malformation
Mother and father	6 months old	2 years	Neuromuscular degenerative disorder
Mother	18 months old	12 years	Cancer
Mother	8 years old (approx)	18 years	Rare degenerative syndrome
Mother	5 years old (approx)	11 years	Cancer
Mother	<6 months old	12 years	Cystic fibrosis
Mother and father	6 months old	2 years	Leukodystrophy
Mother and grandmother	<6 months old	2 years	Rare metabolic disorder
Mother	2 years old (approx)	4 years	Cancer
Mother	5 years old (approx)	5 years	Cancer
Mother and father	<1 week old	4 years	Rare syndrome of multiple congenital abnormalities
Mother	12 years old	12 years	Cancer
Mother	6 years old	11 years	Cancer

*Note: 20 families were interviewed but only 19 interviews were used for analysis.



For more information about the
National Palliative Care Program,
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