

**Title:**

Elements of optimal paediatric palliative care for children and young people: an integrative review using a systematic approach

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**Keywords:**

Palliative care, paediatric, children, model of care

## **Abstract**

**Word Count:** 234 words

*Background:* Models of palliative care need to address the unmet needs of children, young people and families.

*Objective:* To undertake an integrative review to identify the key elements of optimal paediatric palliative care from the perspectives of children and young people with palliative care needs and their parents.

*Data sources:* Electronic databases including CINAHL; Medline; PsycINFO and AMED searched using combined terms for palliative care, service models and children along with reference lists of included studies.

*Study selection:* Peer reviewed empirical studies reporting on evaluation of paediatric palliative care by children and young people with palliative care needs (0-19 years), or their families, published in English, between 2000 and 2013. The views of health professionals and grey literature were excluded. Quality appraisal completed by two researchers, consensus reached following discussion.

*Data extraction and synthesis:* Data extracted by two researchers, entered into an electronic proforma and synthesized using a narrative approach.

*Results:* Seven studies were identified of which two were quantitative, one was qualitative and four were mixed methods. Synthesis highlighted the need for tailored support enabling flexibility in care, with specific reference to location of care and access to psychosocial support, 24 hour specialist support, respite care and sibling support.

*Conclusions:* Paediatric palliative care should be flexible, responsive and tailored to the needs of children and their families. Robust evaluation of models of care that incorporate these elements is required to inform optimal care.

## Introduction

In 2010, 1229 infants ( $\leq 1$  year) and 507 children (aged 1 – 14 years) died in Australia (Australian Institute of Health and Welfare, 2012). The actual number of children and young people who required and/or accessed paediatric palliative care services is unknown. A proportion of these deaths were related to congenital anomalies (26% of infants), cancer (17% of children) and diseases of the nervous system (11% of children), all of which are known to result in progressive debilitation and significant symptom burden (Australian Institute of Health and Welfare, 2012). It is likely that many of these children, young people and their families would have benefited from access to paediatric palliative care but unknown what proportion did benefit. Paediatric palliative care encompasses:

*“....the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.”* World Health Organisation (1998, p. 8)

Whilst adult specialist palliative care services care predominately for people with cancer, paediatric specialist palliative care services care for children, adolescents and young adults with a wide range of life limiting conditions, including neurological, genetic, respiratory and metabolic conditions as well as cancer (Chan & Webster, 2013; Clark, Sheward, Marshall, & Allan, 2012; Department of Health Western Australia, 2009; NSW Health, 2011). The development of specialist paediatric palliative care services in the 1990's largely evolved out of children's differing illness profiles and developmental needs, and recognition of the importance of providing family centred care. Family centred care is defined as 'an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships

among health care providers, patients, and families' (Institute for Patient and Family Centred Care, 2010)

In Australia, specific state-level plans for paediatric palliative care are current in New South Wales (NSW) (NSW Health, 2011), Victoria (Department of Human Services Victoria, 2008) and Western Australia (Department of Health Western Australia, 2009). Most Australian paediatric health care services care for children and adolescents up to the age of 16 years (NSW Health, 2010) but variance in the age at transition to adult services is noted (Greater Metropolitan Clinical Taskforce, 2006).

Similar to other parts of the developed world, some Australian state based health services are currently trying to configure the best models of paediatric palliative care that are family centered and have the capacity to provide care over a large geographical area, for clinically diverse populations with varying levels of need. It is estimated that approximately 160 children per annum accessed specialist paediatric palliative care in 2006 - 2008 (NSW Health, 2011). However, while Australian specialist paediatric palliative care occasions of service data is available, there is no mechanism to capture the extent to which children, young people and families have accessed additional palliative care services from primary health care providers. There is also minimal data regarding the use of paediatric palliative care services by children, young people and families from socially disadvantaged, vulnerable or diverse cultural backgrounds, including Aboriginal and Torres Strait Islander families (NSW Health, 2011). This paper has adopted a definition of model of care as that which 'describes the delivery of health care within the broader context of the health system' (Davidson, Halcomb, Hickman, Phillips, & Graham, 2006, p. 49). Determining the elements of care that are important to children, young

people and families in relation to end of life care is an important priority to inform the development of models of paediatric palliative care.

### **Aim:**

We aimed to identify the key elements of optimal models of paediatric palliative care from the perspectives of children and young people with palliative care needs and their parents.

### **Method**

An integrative review was undertaken to identify the child, young person and family perspectives on the important elements of care within any model of paediatric palliative care. Integrative review methodology was adopted as it would allow for the data from diverse sources (quantitative, qualitative and mixed method studies) to be considered and provide a more holistic understanding of this topic from the consumer perspective (Whittemore & Knafl, 2005). A systematic approach was used to identify included studies, appraise their quality, extract and analyse data and present findings in a usable format (Whittemore & Knafl, 2005). Synthesis of the data was via narrative analysis (Popay et al., 2006).

### *Eligibility criteria*

Empirical studies of any design were included if they were reported in an English-language peer-reviewed journal, published between 2000-13 and reported primary data evaluating models of paediatric palliative/hospice care for children and young people aged 0 – 19 years and/or their parents from the perspectives of children/ young people/parents themselves.

### *Information sources and search strategy*

Electronic databases were searched in December 2012 and included Cumulative Index of Nursing and Allied Health Literature (CINAHL); Medline; PsycINFO and Allied and Complementary Medicine Database (AMED). Searches combined terms for palliative care, service models and children (see Box 1 for an example); terms for palliative care were those recommended by the Australian knowledge network, CareSearch (CareSearch, 2013). The reference lists of all included reviews were searched manually for further relevant articles.

### *Study selection*

Articles returned from the electronic database searches were imported into Endnote (version X5) and coded by two researchers (CV and NB) against inclusion criteria.

### *Data collection and items*

Data were extracted by two researchers (CV and NB) and entered into an electronic proforma in Word. Data items extracted included the country, level of evidence, focus, study design, sample, intervention, findings, implications and elements of care.

### *Bias rating*

Quality appraisal of potential studies was completed independently by 2 researchers (CV and TL) using the APRAC Guidelines: Evidence evaluation tool (Commonwealth of Australia, 2006). These two researchers then met with a third member of the research team (NB) for discussion to gain consensus (Table 1).

## *Synthesis*

A narrative approach to synthesis was undertaken by two researchers (CV and NB). A narrative approach allowed for the broad range of designs and methods to be integrated. The synthesis followed a combination of methods recommended by Popay and colleagues (Popay et al., 2006), notably tabulation and content analysis (Refer Table 2). Each full text article was read by two independent reviewers and initial theming considered. Following this, both researchers met to discuss and agree on final themes relating to optimal elements of care for paediatric palliative care (Table 2).

Levels of evidence generated by each study were classified according to the National Health and Medical Research Council (NHMRC) classifications I – IV (National Health & Medical Research Council, 2005).

## **Results**

### *Study selection*

The initial search returned a total of 207 articles that, after review against inclusion criteria, resulted in seven articles being included (see Figure 1). A record of excluded articles is available on request.

### *Study characteristics*

*Study design:* Each study was designed to collect satisfaction and needs-related data on existing or newly developed paediatric palliative care services, including hospice and outreach models of care. The majority used a mixed methods design (n=4) (Amery, Rose, Holmes, Nguyen, & Byarugaba, 2009; Kirk & Pritchard, 2012; Monterosso, Kristjanson, Aoun, & Phillips, 2007; Noyes et al., 2013), two were quantitative studies (Knapp et al., 2008; Vickers et al.,



2007) and the remainder a qualitative study (Steele, 2000). No experimental designs were located. Most studies used a combination of surveys and/or interviews to obtain parent and child perspectives on paediatric palliative care. The qualitative study used a grounded theory approach to enhance understanding of family experiences of care (Steele, 2000).

*Location:* The majority of studies were undertaken in the developed world (n=6) with three studies from the United Kingdom and one each from Uganda, Australia, Canada and the United States of America (US).

*Participants:* All studies included parents as participants, and three studies included parents and children / young people (Amery et al., 2009; Kirk & Pritchard, 2012; Noyes et al., 2013).

Collectively, these studies represented the views of 1067 parents/family members and 29 children, 8 of whom were noted as participating passively. The survey based studies had response rates of approximately 50% (Kirk & Pritchard, 2012; Knapp et al., 2008; Monterosso et al., 2007). In one study, recruitment was hampered due to physician concern about potential distress to families even though ethics approval had been obtained (Monterosso et al., 2007).

The age range of children varied considerably across studies, from 0-19 years. One study reported exclusively on children with an oncological diagnosis (Vickers et al., 2007), two studies on non-oncological diagnoses (Kirk & Pritchard, 2012; Steele, 2000) and four studies on both oncological and non-oncological diagnoses (Amery et al., 2009; Knapp et al., 2008; Monterosso et al., 2007; Noyes et al., 2013).

## *Synthesis*

Recurrent findings identified by synthesis are shown in Table 2. Studies identified the need for tailored support to enable flexibility in care, with specific reference to location of care and psychosocial support, 24 hour access to specialist support, respite care and support for siblings.

### *Location of care*

The importance of location of care was explicitly referred to in three of the seven studies (Monterosso et al., 2007; Noyes et al., 2013; Vickers et al., 2007). Each of these studies identified a preference for care at home whenever possible. However, in one study a third (32%) of participants did not express a preference for care at home at the outset of care, with this figure changing to 80% expressing a desire for care at home as the child deteriorated in the last month of life (Vickers et al., 2007). The need for flexibility was also reported by Noyes et al (2013) who found that families often changed their mind about the location of care at short notice following a change in the child's condition.

### *Psychosocial support*

Psychosocial support was explicitly referred to in three of the seven studies (Kirk & Pritchard, 2012; Knapp et al., 2008; Noyes et al., 2013). Psychosocial support throughout the child's illness trajectory and into bereavement for children, siblings and parents were considered to be a crucial element of effective paediatric palliative care (Kirk & Pritchard, 2012; Knapp et al., 2008; Noyes et al., 2013). Supportive counselling was accessed by approximately half the families in a service where parents stated they were highly satisfied with the care provided (Knapp et al., 2008). Parents also expressed a desire to have bereavement support provided by

a professional who knew and had been involved in the care of the deceased child (Noyes et al., 2013).

### *Respite care*

Respite care was identified as important in four of the seven studies (Kirk & Pritchard, 2012; Knapp et al., 2008; Monterosso et al., 2007; Noyes et al., 2013), with the level of access and quantity important determinants of effectiveness. However, one study (Monterosso et al., 2007) identified that respite care was often perceived to be both insufficient and inequitable in terms of access. To enable skilled and optimal care for children and young people with rare and complex conditions, staff are required to understand the child's care needs prior to the period of respite (Monterosso et al., 2007). Similarly, Kirk and Pritchard (2012) found that respite care provides the best support to families when parents trust their child's respite team, while Noyes et al (2013) found that families value respite care provided by hospices. Over a fifth (20-23%) of parents noted that they accessed respite care with this being the second highest service element used (Knapp et al., 2008). Knapp et al (2008) identified that parents were most satisfied when the following were provided: care coordination, expressive therapies, pain and symptom consultation, nursing care, personal care, respite care and supportive counselling.

### *Support is provided by specialists in paediatric care*

Having access to a specialist paediatric team was considered crucial by parents (Monterosso et al., 2007; Noyes et al., 2013), as was access to specialist support across the 24 hour period (Noyes et al., 2013). Most studies identified parents' preference for paediatric practitioners to provide effective care for children / young people with palliative care needs, rather than having

to source support from services with adult palliative care expertise (Kirk & Pritchard, 2012; Monterosso et al., 2007; Noyes et al., 2013; Vickers et al., 2007).

### *Sibling support*

In one of the studies parents reported support offered to siblings throughout the palliative care phase and afterwards into bereavement as valuable and important (Kirk & Pritchard, 2012).

Sibling support that was considered most helpful included: arranged activities, opportunities for networking with other siblings within the hospice environment and indirect sibling support provided through respite care for the unwell child, allowing siblings to spend more quality time with their parents. It was noted that additional activities and focus for older siblings in their mid to late teens was considered beneficial (Kirk & Pritchard, 2012).

### *Other*

The grounded theory study examined family perspectives on caring for a child with neurodegenerative life threatening illness dying at home (Steele, 2000) and identified four key themes, namely: entering unfamiliar territory, shifting priorities, creating meaning and holding the fort. Parents described the additional demands they experienced as they navigated uncharted territory and their feelings of isolation created by caring for a dying child at home with these feelings moderated by having sustained and positive relationships with health care professionals. Although not explicitly stated, it is implied that parents valued their relationships with primary health care providers in the community and tertiary setting.

A study undertaken in a developing country where access to basic needs of life is limited, not surprisingly found that the provision of medications for pain and symptom control, food and basic support needs such as blankets, mosquito nets and small amounts of money were most

valued by parents (Amery et al., 2009). In this study, both children and parents appreciated the volunteer play and education service provided by the palliative care service, and the opportunity to develop supportive relationships with other children and staff. Location of care was not identified by parents as a concern, even though the palliative care service provided care to children in hospital and in the community (Amery et al., 2009).

## **Discussion**

This review set out to identify the key elements enabling optimal paediatric palliative care for children, young people and their parents. Whilst the outcomes of this review cannot provide definitive information on effectiveness due to the lack of high quality data, it can provide insights into what parents perceive as being important when caring for a dying child. In particular, the evidence emphasised the need for tailored support to enable flexibility in care and highlights the importance of location of care, psychosocial support, 24 hour specialist support, respite care and support for siblings. Moreover, this review emphasises the need for additional data to understand the perspectives of children in relation to their end of life needs.

Service provision across various locations of care (inpatient and ambulatory care) as well as being close to home was noted as a key element to enable optimal paediatric palliative care. One of the major challenges for services is to deliver this care irrespective of where the child and their family live, which is a considerable challenge in Australia with its dispersed population (Hynson & Drake, 2012). In order to deliver care, regardless of geography, it may be more appropriate and effective for specialist paediatric palliative care teams to support the child's usual paediatric team to provide primary palliative care, with the specialist palliative care team taking on this role and intervening if the child, young person and/or family have more complex care needs. This requires specialist paediatric palliative care services to work in collaboration

with other primary palliative care providers such as community based health care providers, general practitioners, generalist community nursing services and community based palliative care services (Department of Health Western Australia, 2009; Department of Human Services Victoria, 2008; NSW Health, 2011). Adopting a primary palliative care model ensures that families continue to have access to specialist paediatric expertise (Monterosso et al., 2007; Noyes et al., 2013). Any paediatric palliative care model that is developed needs to be based within principles of family centred care, ensure 24 hour access to care and access to specialist palliative care as required. Based on the evidence in the literature, a primary palliative care model can be potentially delivered via: a consultative model; or 'pop-up model' (NSW Health, 2011).

#### *A consultative model*

A consultative model of paediatric palliative care is configured to provide specialist support and advice to the child's primary palliative care team. In this model, the child/ young person and family are cared for by their usual health care team ensuring continuity of care throughout the child's illness trajectory. Ideally specialist palliative care advice is provided by a paediatric palliative care service. Where that is not possible, an adult palliative care service providing care ought to be working in partnership with the primary palliative care team, including the paediatric specialists, so as to ensure that they are providing the most appropriate paediatric palliative care. This consultative model maximises the availability of the relatively few specialised paediatric palliative care professionals (NSW Health, 2011) and ensures that the unique palliative care needs of children, young people and families are met, irrespective of diagnosis. This requires supporting the primary palliative care team to deliver the best evidence based paediatric palliative care. One of the challenges of this model is that the small numbers and

sporadic nature of paediatric palliative care makes it difficult for primary palliative care professionals to maintain their capabilities in this area.

*'Pop up team – shared care' model of palliative care*

In response to these issues and to strengthen the consultative model, the potential for a *'pop up team – shared care' model of palliative care* has been proposed (NSW Health, 2011). This negotiated model of care originally developed for rural/remote adult services (White et al., 2004) includes tailoring a team around a child / young person and their family's unique needs, composed of primary palliative care providers (primary health services, community based services) as well as specialist paediatric palliative care providers. Such teams are quickly established and responsive to need, and can remain in place for the entire illness duration from diagnosis through to bereavement. The policy framework for the pop up model describes the need to develop triggers for referrals, re-assessments and re-referrals to ensure timely care is provided (NSW Health, 2011). Care coordination is noted as a central component for the proposed model of care, from either a primary or specialist care provider, with roles and responsibilities of all team members negotiated and made explicit. After hours support via shared care is proposed to enable statewide support (NSW Health, 2011). As yet, evidence is lacking for this pop-up model. However, this model does address the areas that this review has identified as being important to children and families, namely: flexibility in location of care, psychosocial support through to bereavement and the availability of 24 hour specialist support. What is less clear is how this model would ensure other key elements identified in this review, such as respite availability, support for siblings and access to paediatric professionals at all times, would be provided. However, given the expansion in technological innovations, access to

virtual specialist paediatric professional support could be made possible through e-health platforms and access to parental and sibling support via on-line peer-support forums.

Access to skilled respite care for children / young people requiring palliative care is required to enable their families to have a break and to better support siblings (Kirk & Pritchard, 2012; Knapp et al., 2008; Monterosso et al., 2007; Noyes et al., 2013). The degree to which respite care is accessible for children / young people and families (either through inpatient hospice care or community care) within Australia remains unclear, but it is evident that a creative approach is required to ensure that all children in need have access to this support regardless of where they live.

In Australia, the development of specialist paediatric palliative care services has been ad hoc and local rather than planned and national (Hynson & Drake, 2012; Monterosso, Kristjanson, & Phillips, 2009) with various models of paediatric palliative care evolving in accordance with the strengths of local clinicians, the needs of the local region and available resources. Jurisdictional palliative care strategies in NSW, VIC, WA and SA are trying to address this issue with state-wide models of paediatric palliative care in various stages of implementation. The extent to which consumers have been consulted or contributed to the development of paediatric palliative services is not clear. There is some discussion of strategies to involve consumers evident within policies developed by NSW and Victoria (Department of Human Services Victoria, 2008; NSW Health, 2011). However this review, shaped by perspectives of parents (and a small proportion of children / young people), outlines key areas that do correlate with many areas of policy and current service delivery.



This review also identified that parents' perceived needs may be different for families in developing nations or in very remote and/or underserved communities, where addressing the basic needs of life are required before higher level palliative care needs can be addressed.

*Limitations of this review:*

The key limitation of this review relates to the lack of empirical studies to identify best practice paediatric palliative care or to identify which components of a model of care contribute to optimal care, from the perspective of parents and children / young people. Of significance is the very small number of children / young people included across samples so we are working with data principally taken from a proxy, being their parents. This lack of empirical evidence does not correlate with an absence of innovative or excellent practices. However, this does show a lack of evaluation and outcome measurement to inform future care / improvement. It is clear that there is a need for prospective, longitudinal studies that look at needs separately from satisfaction. Inclusion criteria for this study focused on the perspectives from parents and children only in relation to paediatric palliative care needs. This may have excluded valuable information and insights from health care professionals working within paediatric palliative care. Grey literature was also excluded and this could also contribute to the understanding of this complex area of health care. Finally this review only included papers written in English and published from the year 2000. Although evidence is available to suggest limiting searches to English language data only does not create a bias (Morrison et al., 2012), the testing of bias is not yet available in relation to qualitative and poorer quality studies upon which this study relies.

### *Implications for research:*

Outcome measurement in relation to models of paediatric palliative care is not described within these studies and requires further attention. Furthermore, an analysis of unpublished data from service satisfaction surveys and published policy documents would be useful. Consideration also needs to be given to the benefits and limitations of models of care for either all children / young people with palliative care needs or condition specific models. It is difficult to make recommendations, given the absence of outcome data for current models of care. Evaluation of shared specialist palliative care models of care involving adult and paediatric services and the pop-up model of care are urgently required, especially given the fact this is the model advocated by NSW policy (NSW Health, 2011), using appropriately designed studies to better inform future optimal models of care. Alternate operationalisations of family centred care should guide prospective longitudinal comparisons. Furthermore, investigating mechanisms to allow children's perspectives to be integrated into this outcome measurement is warranted. There is also a need to develop and test novel models of respite care so that this element of care can be better addressed.

### **Conclusion**

Family centred care and empirical knowledge should drive the development of optimal models of paediatric palliative care for children and young people with life limiting illness and their families. This review outlines key elements that are important to children/ young people requiring palliative care, and their families. However, none of the reviewed studies provide rigorous evaluative data and so this information should be read as informative rather than definitive in nature. Despite this, many of the categories found resonate with key state policy documents within Australia and therefore evaluation of the implementation of such plans will be useful. The overarching theme found by this review is that of children / young people and

parents needing access to tailored support including flexibility in location of care, psychosocial care, 24 hour specialist support, respite care and support for siblings. The development, implementation and evaluation of models of care to enable optimal care for children / young people with life limiting illness, and their families, whilst being a high priority is complex. However with ongoing focus, clear information of need alongside service capability will evolve and continue to inform improved care and support for all who require it.

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