Specialist paediatric palliative care services: what are the benefits?

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ABSTRACT

Background The number of children and young people (CYP) living with life-limiting and life-threatening conditions is rising. Paediatric palliative care is a relatively new aspect of healthcare, the delivery of which is variable, with a wide range of healthcare and voluntary sector providers involved. Policy recommendations are for Specialist Paediatric Palliative Care (SPPC) services to be supported by a physician with specialist training.

Aim To examine the research evidence regarding the distinct benefits of SPPC services, with ‘Specialist Paediatric Palliative Care’ defined as palliative care services supported by a specialist physician.

Method Systematic review of studies of SPPC services published in English from 1980 to 2016. Keyword searches were carried out in medical databases (Cochrane, PubMed, EMBASE, CINAHL and AMED) and a narrative synthesis.

Results Eight studies were identified, most of which were retrospective surveys undertaken within single institutions; three were surveys of bereaved parents and three were medical notes reviews. Together they represented a heterogeneous body of low-level evidence. Cross-cutting themes suggest that SPPC services improve the quality of life and symptom control and can impact positively on place of care and family support.

Conclusions Current evidence indicates that SPPC services contribute beneficially to the care and experience of CYP and their families, but is limited in terms of quantity, methodological rigour and generalisability. Further research is necessary given the significant workforce and resource implications associated with policy recommendations about the future provision of SPPC and to address the need for evidence to inform the design and delivery of SPPC services.

INTRODUCTION

With advances in medical treatments and the use of medical technology, a growing number of children and young people (CYP) live with life-limiting conditions (LLCs) and life-threatening conditions (LTGs).¹ ² This includes CYP who live with conditions where curative treatment is feasible but can fail, while for others, there is no known cure.³ Ensuring sustainable healthcare services that can effectively meet the needs of these CYP and those of their families presents a significant challenge.

Palliative care for CYP has been defined as “an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of the quality of life for the CYP and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.”⁴ Globally, it is estimated that seven million CYP (aged 0–19) could benefit from palliative care services,⁴ with at least 49 000 in the UK.⁵ However, most countries have no paediatric palliative care services, including hospices.⁴ Where paediatric palliative care services have developed, this has been largely as a result of the determination of motivated individuals and charitable funders.⁶ ⁷ The type and availability of services vary geographically due to the wide range of healthcare and voluntary sector providers involved.⁴

Specialist Paediatric Palliative Care (SPPC) services are defined in UK and European standards as those supported by a physician with specialty training (a consultant) in paediatric palliative medicine.⁸ ⁹ ¹⁰ However, SPPC is yet to become an established medical subspecialty, and few countries have doctors trained to this level.¹¹ As a result, there is a tension between this standard of care and the many existing services which specialise in the...
provision of paediatric palliative care but lack the support of specialty-trained physicians.

OBJECTIVE
The objective of this systematic review is to contribute to the debate regarding the design of paediatric palliative care services by specifically examining SPPC, defined as a palliative care service supported by a physician with specialty training in paediatric palliative medicine, and asking “What are the distinct benefits of these SPPC services to CYP and their families?” The review also provides an opportunity to identify evidence gaps for further research.

DESIGN
The Centre for Reviews and Dissemination (CRD) guidance for systematic reviews in healthcare and the Cochrane Collaboration’s Handbook for Systematic Reviews of Interventions informed the review’s methodology.11 12 The structure and content were informed by the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines.13 A protocol has been registered and published on the PROSPERO database (ref no: CRD42016050677).

Search strategy
Information sources
The following electronic databases were searched from September 2015 to January 2016 with the last search on 7 January 2016:
- Cochrane Central Register of Controlled Trials and Cochrane Database of Systematic Reviews
- PubMed (1980 onwards)
- EMBASE (1980 onwards)
- CINAHL (1981 onwards)
- AMED (1985 onwards)

After initial broad scoping searches, the search terms outlined in table 1 were used to perform a focused systematic search. The population search was carried out first, followed by the intervention search. The search was carried out with the advice of the University of Warwick specialist librarian. Hand searching of references, ‘cited by’ and PubMed-related articles link searches were also carried out.

Inclusion/exclusion criteria
Inclusion and exclusion criteria are outlined in table 2.

Study selection
Duplicate articles were removed. Titles and abstracts were screened, followed by examination of the full text. Articles were assessed for inclusion independently by three reviewers (SM, KB and AM).

Data management
Two reviewers extracted relevant data to an Excel spreadsheet (AM and KB), which was independently checked for accuracy and detail by SM. The team discussed any disagreements.

Data synthesis
The included studies were compared and contrasted using a data extraction table. There were no comparable statistics and therefore a systematic narrative synthesis14 was undertaken, identifying cross-cutting themes from each study. The narrative was reviewed at intervals by LS, our patient and public involvement coauthor, with feedback provided on relevance to family experience and by JD for intellectual content.

RESULTS
Study selection
Seven hundred and seventy relevant articles were identified. Seven hundred and fifty-five were excluded after title and abstract screening and the removal of duplicates, leaving 15 articles. Three of these were conference abstracts of ongoing studies which were not available as full-text articles or as unpublished studies from the authors and were therefore excluded. After applying the inclusion and exclusion criteria to the remaining 12 articles, 4 were excluded because they did not concern SPPC services with specialist medical support, leaving 8 articles. This process is shown in figure 1. Study characteristics are summarised in table 3.

Study location
Included studies were from the USA,15–18 the UK,19 Germany,20 Australia21 and Canada.22

Study quality
The studies represented a heterogeneous body of evidence;15 seven were retrospective studies;15–19 21 22 three were surveys of bereaved parents,15 17 22 one was an epidemiological study19 and three were medical notes reviews,16 18 21 one of which included an economic analysis.18 There was one prospective longitudinal survey.20 There were no randomised-controlled trials or systematic reviews. All had clear aims and used appropriate methodology and approached the ethical issues. All acknowledged the limitations in their study design and recruitment strategies, and data were collected in a way that would address the research aims. All gave clear descriptions of their data analysis, results and findings.23

All had been published since 2012 and were carried out within single institutions or services. The largest study in terms of patient numbers was an epidemiological study, which looked at data regarding 2508 CYP but was limited by missing data items.19 The notes review studies examined the care of a total of 611 CYP 16 18 21 Three studies concerned only CYP with cancer,15 19 22 The other five studies concerned services for CYP with non-malignant conditions as well as those with cancer.16–18 20 21

Four studies made use of questionnaires with caregivers;15 17 20 22 three were surveys of bereaved parents.15 17 22 The total number of bereaved parents included in these studies was 200. Time since bereavement ranged from 7 months to over 4 years.14 17 22 Response rates for postal surveys of a total number of bereaved parents in a time period were 65/192 (37%)17 and 60/166 (36%).17 A response rate of 75/140 (75%)
was achieved where eligibility criteria were applied. The highest response rate for a questionnaire survey was 93% (40/43), with the questionnaire administered face to face with family members at the time they were receiving care from the SPPC services. This study also attempted the assessment of children by self-report but due to young age and clinical condition this was possible with only three CYP.

### Key themes

Four key themes about how SPPC services can impact on CYP and their families were identified. These related to:

1. **Quality of life**
2. **Symptom control**
3. **Place of care**
4. **Family support**

#### Quality of life

The studies provide evidence that SPPC services contribute to improving the quality of life of CYP and family through emotional support, care planning and help with medical decision making, as well as through the management of distressing physical symptoms. Improved satisfaction with care was reported once SPPC services were involved.

#### Symptom control

Pain and symptom management was described as one of the main reasons for referral to SPPC. Improvements in children’s symptom control with the involvement of the SPPC team were reported by parents retrospectively. With the involvement of SPPC services, more care, including symptom management, was delivered in the home environment alongside other support for caregivers and practical support.

#### Place of care

Three studies provided evidence to suggest that referral to SPPC is associated with fewer admissions to hospital or a reduced length of stay. The involvement of SPPC services was associated

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**Table 2: Inclusion and exclusion criteria**

| PICOS dimension | Inclusion | Exclusion |
|-----------------|-----------|-----------|
| **Population**  | Children and young people aged from 0 to 18 years (inclusive) | Studies concerning neonatal palliative care |
|                 | Studies concerning specifically young people making the transition to adult services | Adult studies |
| **Intervention**| ‘Specialist Paediatric Palliative Care’ defined as a palliative care service supported by a physician with specialty training in paediatric palliative medicine, as per current recommendations and service specifications | Paediatric palliative care services that did not meet the specialist specification, including hospice services, and services supported by paediatricians who had not received specialty training in paediatric palliative medicine (where it was possible to establish this) |
| **Comparator**  | Usual care or palliative care that was provided by other types of services | Neonatal palliative care services |
| **Outcomes**    | Any formal measure of evaluation concerning the acceptability or effectiveness of the intervention | Adult palliative care services (who may be catering for paediatric patients) |
| **Study design**| Any evaluative study design | Any other usual care |
| **Publication** | Databases were searched from 1980 onwards | Review articles, descriptive or theoretical papers that did not present original research findings |
|                 | Unpublished grey literature | Non-English language papers |
|                 |                             | Articles only available in abstract form where no full text is available (the authors were contacted) |
|                 |                             | Voluntary sector reports |

PICOS, Population, Intervention, Comparators, Outcome, Study design.
### Table 3  Study characteristics

| Study                  | Participants                                                                 | Intervention                                                                 | Findings                                                                 |
|------------------------|-------------------------------------------------------------------------------|------------------------------------------------------------------------------|--------------------------------------------------------------------------|
| Sheetz et al<sup>17</sup> | Parents of 65 children who had died while under the care of the programme, CYP with a range of LLCs and LTCs, including cancer and complex chronic conditions, most frequently genetic/ congenital, neuromuscular and cardiovascular conditions. | SPPC programme: multi-disciplinary team including paediatrician and nurse practitioner board-certified in paediatric palliative medicine, nurse manager, social worker, chaplain. Hospital-based inpatient consultation service and home consultation service after discharge. Age range prenatal–36 years. | 65/192 responded (37%). 37% of children had died at home, 53% at the hospital, 8% at another hospital and 2% in a long-term care facility. 21 were also receiving hospice services at the time of death. 95% agreed or strongly agreed that the SPPC team helped them make decisions about their child’s care, 5% disagreed. 76% felt the team had helped them set goals for care (others unsure or disagreed), 78% agreed that those goals of care were subsequently met. 13% unsure, 10% disagreed. 95% felt supported in their choices for their child’s care. Also, 78% felt that physical pain/distressing symptoms were controlled at the end of life, 22% unsure or disagreed. 71% felt symptoms other than pain were controlled adequately. High levels of parent satisfaction with SPPC. SPPC had an important role in education: decision making, the process of death and aspects of the medical system. Feedback included a desire that the team were involved sooner. |
| Fraser et al<sup>19</sup> | 2508 patients aged 0–19 years with cancer from 1990 to 2009, who were in the catchment area for the SPPCS. | SPPC based at a child’s (aged up to 35 years) hospice with a full-time consultant from 2004. 24/7 on-call medical service and a home visiting service. | 27.7% of those who had died were referred to SPPC (less than a third), 182 had died and had been referred, 475 had not been referred before they died. No significant difference in terms of demographics. Most commonly referred were those with central nervous system (CNS) tumours. Referral to SPPC was associated with a significantly lower rate of planned hospital admissions (incidence rate ratio=0.60, 95% CI 0.43 to 0.85). There was no significant difference in emergency (which comprised 97% of admissions) or total hospital admission rates. Children with CNS tumours had significantly less hospital admissions compared with those with leukaemia (may be due to the nature of treatment). |
| Groh et al<sup>20</sup>  | All primary caregivers of severely ill children receiving SPPC via the Paediatric Palliative Home Care (PPHC) team for the first time between April 2011 and June 2012. 40 families. 18 CYP died before study ended. 16 of them at home. Wide range of diagnoses, including cancer and complex chronic conditions. | Multiprofessional SPPC team consisting of three paediatricians, two nurses, a social worker and a chaplain, all with special training in palliative care. 24/7 on call. | SPPC was associated with improved satisfaction with care and quality of care. Significant improvement in children’s symptom control and quality of life as perceived by parents. Parents own quality of life and burden relief significantly increased and psychological distress and burden decreased. SPPC led to reduced rates of hospitalisation and improved caregiver satisfaction with care received, including psychological support and support of activities of daily living. Caregivers felt more informed on disease situation and progression, better taken care of and improved communication with child. Psychosocial support was identified as the most helpful aspect of care. 24/7 on-call service and time for detailed conversations highly valued, as were support with practicalities, for example, Advance Care Planning, equipment. There was a median of three hospitalisations (including planned), two emergency room visits in the last 6 months of life. Median of 24 home visits (1–121), home visit frequency varied. Symptom control was important, as were ‘goals of care’ discussions, which happened a median of 16 days before death (0–116). 25 had home Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). 15 CYP were aware of impending death (recorded)—tended to be older CYP. 16 children died at home, 20 died in hospital. 16 had recorded preferred place of death. Conclusion was that children who die of complex chronic conditions spend most of their last 6 months at home; community SPPC contributes substantially to their care and comfort. |
| Niswander et al<sup>16</sup> | 36 children who died with a wide range of diagnoses, including cancer, enrolled in the programme for a median 1.1 years before they died. | A team consisting of paediatric nurses, paediatric nurse practitioners, a paediatrician board-certified in hospice and palliative medicine, child life specialists, social workers, chaplain and expressive therapists. | Continued |
| Study            | Design and research questions                                                                                                                                                                                                 | Participants                                                                 | Intervention                                                                                                                                                                                                 | Findings                                                                                                                                                                                                                     |
|------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Postier et al    | What is the healthcare utilisation by children prior to enrolment in SPPC compared with the period after enrolment? Retrospective cohort study of electronic medical records and economic analysis. Minneapolis, USA. | 425 children with a range of diagnoses aged 1–21 under the care of SPPC for at least 1-day between 2000 and 2010. | 24/7 access and care coordination through home visits by nurses, social workers, child life specialists, chaplains, music/massage therapists, physicians and volunteers. | No. of hospital admissions didn’t change. Length of stay decreased by 2 weeks post-SPPC involvement, with a significant drop in healthcare costs. Largest decreases in resource utilisation for the non-malignant group—reduced length of stay in hospital with SPPC involvement, decrease in hospital charges for those under SPPC >6 months. |
| Herbert et al    | What are the characteristics of the population cared for by the SPPC service? What outcomes are the SPPC achieving and how has the service developed? Retrospective cohort review of medical notes of children who were referred to the service in a 2-year period. Brisbane, Australia. | 150 patients referred over a 24-month period. Wide range of diagnoses. | The SPPC developed from the existing paediatric oncology palliative care service at the Royal Children’s Hospital (RCH) and incrementally expanded over a period of 3.5 years, commencing with a dedicated paediatrician trained in palliative care, followed by nursing staff and the addition of dedicated allied health staff from 2010. Offers biannual training days and videoconferencing. 24/7 telephone support. | Median duration of contact time with the service was 83 days. Non-oncology diagnosis was likely to result in longer use of the service (>6 months). 41% of children died at home and 48% died at hospital. Reasons for referral: pain and symptom management (29%), advanced care planning (25%), community care planning (21%) and end-of-life care (26%). |
| Friedrichsdorf et al | How does end-of-life pain and symptom management in children with advanced cancer who received care exclusively from oncology compare with those who received concurrent SPPC home care? What are the differences between the two groups regarding health outcomes, including quality of life and location of death. Retrospective cohort study of bereaved parents whose children died of cancer. Minneapolis, USA. | Final sample of 60 bereaved parents of children who died of cancer between 2002 and 2008 at a US tertiary paediatric institution. | Paediatric palliative care (PPC) PPC nurses, social workers and chaplaincy. A PPC physician and/or paediatric oncologist or oncology advanced practice registered nurse. 24/7 nursing on-call for home visits. | No significant difference in prevalence of symptoms between those referred to SPPC and those who were not. There was a trend towards greater perceived suffering from pain in the group who were not referred to SPPC group. Seizures and nausea/vomiting were the most successfully managed in both groups. More parents in SPPC group wanted their child to die at home and had an opportunity to plan this. More children in PPC group did die at home. SPPC children had more fun and more likely to have an experience, which added meaning to their life. |
| Kassam et al     | Is referral to SPPC associated with improved end-of-life care communication for children with advanced cancer and their families? Questionnaire survey and medical record review examining differences in end-of-life communication for children with advanced cancer who were referred to a SPPC team. Toronto, Canada. | 75 bereaved parents | Paediatric Advanced Care Team (PACT) team: four palliative care physicians, three nurses, two grief support coordinators and one administrative assistant. PACT also draws on the special knowledge of other professionals and volunteers like chaplains, social workers, nurses, bioethicists, physicians, pain experts, volunteers and parents. | Most frequent communication was DNACPR discussion. Least frequent was discussion of death and dying when appropriate and advice on how to talk to child about this. Univariate analysis showed parents more likely to have the following five communication elements if a palliative care team were involved: Discussion of death and dying with parents and with the child, guidance on how to talk to their child, preparing parents for medical aspects of death and sibling support. |

CYP, children and young people; LLCs, life-limiting conditions; LTCs, life-threatening conditions; SPPC, Specialist Paediatric Palliative Care.
with care planning discussions and considering a preferred location of death.\textsuperscript{16, 22} More CYP died at home with SPPC involvement than not.\textsuperscript{15, 20} Differences in terms of both diagnosis and geographical location of the family home contributed to the location of death. In one study, CYP with a cancer diagnosis were more likely to die at home if they lived in a rural location; CYP with non-malignant disease were more likely to die in a tertiary hospital.\textsuperscript{21} However, there was evidence that ‘goals of care’ discussions tended to occur relatively late, with the median time before death that this discussion took place being 16 days.\textsuperscript{16}

Family experience

There were several areas in which SPPC intervention was reported as contributing to an improvement in family members’ quality of life.\textsuperscript{20, 22} Access to services 24 hours a day, 7 days/week was valued.\textsuperscript{20} Perception of psychological support and support for carrying out ‘day-to-day activities’ increased, and there was a decrease in anxiety and depression among parents.\textsuperscript{20} SPPC teams provided support with medical decision making,\textsuperscript{16, 17} including discussions about resuscitation,\textsuperscript{16, 22} help with communication between family members, including with their child, and with other healthcare teams.\textsuperscript{17, 20, 22} The SPPC team played an important role in educating parents about both the process of death and aspects of the medical system.\textsuperscript{17}

Low referral rates to SPPC services were described\textsuperscript{19} and the average length of time that a child was under the care of SPPC varied from 20 days to over 1 year.\textsuperscript{16, 18, 21, 22} Feedback from families included a desire that SPPC was involved earlier on in the course of a child’s illness.\textsuperscript{17}

DISCUSSION

This review set out to investigate the current evidence regarding the distinct benefits to CYP and their families of care provided by SPPC, defined as a palliative care service supported by a physician with specialist training. A small number of studies met the inclusion criteria, all of which had been published within the last 5 years. All of these were single-centre studies with relatively small patient numbers and rank low in the hierarchy of evidence due to their methodological limitations.\textsuperscript{12} This is a well-recognised problem in palliative care research, due to clinical and ethical challenges, and brings into question the value of systematic reviews in this subject area.\textsuperscript{24} Specific methodological challenges exist around gatekeeping of participants by clinicians,\textsuperscript{25} which was described as a barrier to recruitment in one study.\textsuperscript{22} In surveys, families were found to be unreachable by phone or post, did not respond or were ineligible to participate due to language barriers.\textsuperscript{15, 17, 20, 22} Where families did respond, they are likely to have been particularly motivated to participate, and therefore the survey findings may not be generalisable to a more diverse population of families. One study tried to collect the views of CYP but found this was not possible.\textsuperscript{20}

Benefits of SPPC

Despite the limited quality of the evidence, there are cross-cutting themes from the eight studies suggesting that SPPC may enable improved quality of life for CYP and parents, improved symptom control, has an impact on the place of care and an increased likelihood that a preferred place of death is achieved.\textsuperscript{16, 17, 20–22}

Service delivery

The review is timely as the specialty of paediatric palliative medicine further develops, with international standards, specifications and recommendations.\textsuperscript{8–10} Systematic consideration of the available evidence to support the development of services and policy is necessary, particularly as the number of CYP with LLCs and LTCs rises.

There is ongoing emphasis on place of death as an outcome measure in palliative care, despite a limited evidence base to support this.\textsuperscript{27} ‘Choice’ in end-of-life care is frequently highlighted in policy,\textsuperscript{28} and families desire the option of care being provided at home.\textsuperscript{29} This review suggests an association between referral to a SPPC team and opportunity to first express preferences for goals of care and location of death and then achieve it,\textsuperscript{15, 16, 22} although there was some evidence that this occurred relatively late in the course of illness.\textsuperscript{16} Key factors that enable these discussions have been described as continuous relationships, time for open, honest conversations and the provision of symptom control.\textsuperscript{15, 20, 29, 30}

Although adequate control of symptoms was not always perceived by parents,\textsuperscript{15, 17} there was evidence to suggest that more effective symptom control could be delivered in the home environment with the involvement of an SPPC team.\textsuperscript{13} Further research into symptom management in CYP, including the use of medications and routes of administration, and how this can be delivered in both community and inpatient care settings, is an important focus for SPPC.

SPPC service design

What cannot be ascertained from the available evidence is which elements of SPPC services are associated with the benefits described, the mechanisms by which these benefits occur or the impact of the presence of a specialty-trained physician. This review looked specifically at services with a specialty-trained physician and excluded studies of any other model of care. However, nurse-led paediatric palliative care services and children’s hospice services have also been shown to benefit CYP and their families, particularly in terms of place of care,\textsuperscript{11–14} coordination of care,\textsuperscript{35} and family support.\textsuperscript{36} Research to compare more clearly the different types of services, and how they can effectively work together, would be valuable. Further research to investigate the most effective services for children with differing LLCs would also be of value given the wide variation in disease trajectories, family need and outcomes.\textsuperscript{3}

The benefits of a specialist physician in a service have been broadly described as advanced clinical expertise and academic, educational and strategic leadership,\textsuperscript{37} all of which are important in SPPC as the specialty develops. Securing funding to develop both specialty training and new consultant posts presents a major challenge and will require clear business cases. Future innovation and development of the SPPC workforce and the implementation of new policies, including National Institute for Health and Care Excellence (NICE) guidance,\textsuperscript{26} should be accompanied by robust plans for evaluation.

This review identified only one study which made reference to the value of parental input into the development of SPPC services.\textsuperscript{17} Codesign of services with CYP and families\textsuperscript{28, 29} and work to address possible reasons for low referral rates to SPPC, such as negative perceptions of palliative care among families\textsuperscript{39} and healthcare professionals,\textsuperscript{40, 41} would be highly relevant.

CONCLUSION

Future service development recommendations should address the need for accessible and sustainable SPPC services for all CYP who need them. However, as this review demonstrates, there is limited evidence to inform policy guidance within the overall provision of paediatric palliative care. In the context of a
A systematic review protocol has been published on PROSPERO (ref no: CRD42016050677).

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