Article:

Mitchell, S., Morris, A., Bennett, K. et al. (2017) Specialist paediatric palliative care services: what are the benefits? Archives of Disease in Childhood, 102 (10). pp. 923-929. ISSN: 0003-9888

https://doi.org/10.1136/archdischild-2016-312026

This article has been accepted for publication in Archives of Disease in Childhood, 2017 following peer review, and the Version of Record can be accessed online at http://dx.doi.org/10.1136/archdischild-2016-312026

Specialist paediatric palliative care services: what are the benefits?

Mitchell S [1], Morris A [1], Bennett K [1], Sajid L [2], Dale J [1].

Corresponding Author:
Dr Sarah Mitchell
Warwick Medical School, University of Warwick, Gibbet Hill Road, Coventry, CV4 7AL, UK
Tel: 07986183313
Email: sarah.j.mitchell@warwick.ac.uk

Co-Authors:

- Mr Andrew Morris, Medical Student, Warwick Medical School, University of Warwick, Gibbet Hill Road, Coventry CV4 7AL, UK
- Miss Karina Bennett, Medical Student, Warwick Medical School, University of Warwick, Gibbet Hill Road, Coventry CV4 7AL, UK
- Prof Jeremy Dale, Warwick Medical School, University of Warwick, Gibbet Hill Road, Coventry CV4 7AL, UK
- Miss Laiba Sajid, Acorns Children's Hospice Trust, Sibling Council, Drakes Court, Alcester Road, Wythall, Birmingham, B47 6JR, UK.

Keywords: Palliative Care, Children and Young People, Specialist Services, Effectiveness

Word count: 2574

Specialist paediatric palliative care services: what are the benefits?

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 1980-2016. 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 quality of life and symptom control, and can impact positively on place of care and family support.

Conclusion: 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.

Patient and Public Involvement

The study was designed in close consultation with patient and public involvement (PPI) groups at Acorns Children's Hospice and Birmingham Children's Hospital. LS is 15 years old and a member of Acorns Sibling Council who has provided PPI support to this systematic review. She has advised on

the aims and objectives of the review and revised this draft for clarity. The research team would like to thank her mother, Najma, for her support.

Authorship statement

SM and JD designed the study. SM, AM and KB retrieved and analysed the data, and drafted the article. AM and KB undertook these elements of the review to fulfil the requirements of the SSC2 module of the MBChB course at Warwick University. JD assisted with interpretation of the data. LS and JD revised the article critically for clarity and intellectual content. All authors have approved this version for submission. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding

SM is funded by a National Institute for Health Research Doctoral Research Fellowship (DRF-2014-07-065).

Disclaimer

This article presents independent research funded in part by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Competing interests: None declared

What is already known?

- The numbers of children and young people (CYP) living with life-limiting and life-threatening conditions is rising with continuing advances in clinical medicine.
- There are international recommendations and standards for Specialist Paediatric Palliative Care (SPPC) services but this is a relatively new subspeciality and is inconsistently available.
- The more universal adoption of recommendations and standards requires significant investment of resource, which is difficult to achieve.

What this study adds

- This is the first systematic review of research related to the evaluation of SPPC.
- The review identifies a summary of the evidence that suggests that SPPC provides benefit to CYP and families.
- Key themes have been identified to inform future service development and research in paediatric palliative care.

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 (LLCs) and life-threatening conditions (LTCs) (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 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 (3).” 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 varies 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 (1, 8-10). However, SPPC is yet to become an established medical sub-specialty, and few countries have doctors trained to this level (4). 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 was 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 07.1.2016.

- 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.

Table 1: Search Strategy

Population	Pediatr* / Paediatr* AND (Infant OR Child* OR Adolescen*)
Intervention	Palliat* Special* End-of-life Hospice Terminal care Consultant Physician Delivery of healthcare Service

Inclusion / Exclusion Criteria

Inclusion and exclusion criteria are outlined in Table 2.

Table 2: Inclusion and Exclusion Criteria

PICOS Dimension	Inclusion	Exclusion
Population	Children and young people aged from 0-18 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	Paediatric palliative care services that did not meet the specialist

	supported by a physician with speciality training in paediatric palliative medicine, as per current recommendations and service specifications.	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). Neonatal palliative care services Adult palliative care services (who may be catering for paediatric patients) Any other usual care
Comparator	Usual care or palliative care that was provided by other types of service	
Outcomes	Any formal measure of evaluation concerning the acceptability or effectiveness of the intervention.	
Study design	Any evaluative study design	Review articles, descriptive or theoretical papers that did not present original research findings
Publication	Databases were searched from 1980 onwards. 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

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 synthesis (14) was undertaken, identifying cross-cutting themes from each study. The narrative was reviewed at intervals by LS, our PPI co-author, with feedback provided on relevance to family experience, and by JD for intellectual content.

Results

Study selection: 770 relevant articles were identified. 755 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, four were excluded because they did not concern SPPC services with specialist medical support, leaving eight 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), Australia (21), and Canada (22).

Study quality: The studies represented a heterogeneous body of evidence (13); seven were retrospective studies (15-19, 21, 22); three were surveys of bereaved parents (15, 17, 22), one was an epidemiological study (19) 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 randomized-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 was 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 children and young people (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 seven months to over four years (15, 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%) (15). A response rate of 75/140 (75%) was achieved where eligibility criteria were applied (22). 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 service (20). 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 (20).

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 (16, 17, 20-21), as well as through the management of distressing physical symptoms (17, 21). Improved satisfaction with care was reported once SPPC services were involved (16, 20). One study reported that CYP who were in contact with a SPPC 'had more fun and [were] more likely to have an experience which added meaning to their life' (15) than those who were not.

Symptom control

Pain and symptom management was described as one of the main reasons for referral to SPPC (21). Improvements in children's symptom control with the involvement of the SPPC team were reported by parents retrospectively (15, 20). With the involvement of SPPC services, more care including symptom management was delivered in the home environment (15), alongside other support for caregivers and practical support (20).

Place of Care

Three studies provided evidence to suggest that referral to SPPC is associated with fewer admissions to hospital (19, 20) or a reduced length of stay (18). The involvement of SPPC services was associated with care planning discussions and considering a preferred location of death (16, 22). More CYP died at home with SPPC involvement than not (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 (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 (16).

Family experience

There were several areas in which SPPC intervention was reported as contributing to an improvement in family members' quality of life (20, 22). Access to services 24 hours a day, 7 days per week was valued (20). Perception of psychological support and support for carrying out "day-to-day activities" increased, and there was a decrease in anxiety and depression amongst parents (20). SPPC teams provided support with medical decision making (16, 17), including discussions about resuscitation (16, 22), help with communication between family members, including with their child, and with other healthcare teams (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 (17).

Low referral rates to SPPC services were described (19) and the average length of time that a child was under the care of SPPC varied from 20 days to over one year (16, 18, 21, 22). Feedback from families included a desire that SPPC was involved earlier on in the course of a child's illness (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 five 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 (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 (24). Specific methodological challenges exist around gatekeeping of participants by clinicians (25), which was described as a barrier to recruitment in one study (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 (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 (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 (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 (8-10, 26). 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 (27). “Choice” in end-of-life care is frequently highlighted in policy (28), and families desire the option of care being provided at home (29). This review suggests an association between referral to a SPPC team and opportunity to firstly express preferences for “goals of care” and location of death, and then achieve it (15, 16, 22), although there was some evidence that this occurred relatively late in the course of illness (16). Key factors that enable these discussions have been described as continuous relationships, time for open, honest conversations, and the provision of symptom control (15, 20, 29, 30).

Although adequate control of symptoms was not always perceived by parents (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 (15). Further research into symptom management in CYP including 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 (31-34), co-ordination of care (35) and family support (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 life-limiting conditions would also be of value given the wide variation in disease trajectories, family need and outcomes (3).

The benefits of a specialist physician in a service have been broadly described as advanced clinical expertise, and academic, educational and strategic leadership (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 NICE guidance (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 (17). Co-design of services with CYP and families (28, 38), and work to address possible reasons for low referral rates to SPPC, such as negative perceptions of palliative care amongst families (39) and healthcare professionals (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 growing number of CYP and families who could benefit from SPPC, there is a need for further research, innovation and debate. Robust evaluation of services, care models and professional roles, as well as research to understand the mechanisms by which benefits are delivered to CYP and families, are necessary. These are key considerations for those who are leading the development of SPPC, and for service commissioners.

References

1. Hain R, Heckford E, McCulloch R. Paediatric palliative medicine in the UK: past, present, future. Arch Dis Child. 2012;97(4):381-4.

2. Harrop E, Edwards C. How and when to refer a child for specialist paediatric palliative care. Arch of Dis Child Ed Pract. 2013;98(6):202-8.

3. Together for Short Lives. Children's Palliative Care Definitions. http://www.togetherforshortlives.org.uk/assets/0000/4089/CPC_definitions.pdf.

4. Knapp C, Woodworth L, Wright M, et al. Pediatric Palliative Care Provision Around the World: A Systematic Review. Pediatr Blood Canc. 2011;57:361-8.

5. Fraser LK, Miller M, Hain R, et al. Rising national prevalence of life-limiting conditions in children in England. Pediatrics. 2012;129(4):e923-9.

6. MacNamara-Goodger K, Feudtner C. History and epidemiology. In: Goldman A, Hain R, Liben S, Ed. Oxford Textbook of Palliative Care for Children 2nd ed. Oxford: Oxford University Press; 2012.

7. Beringer AJ, Eaton NM, Jones GL. Providing a children's palliative care service in the community through fixed-term grants: the staff perspective. Child: Care, Health Dev. 2007;33(5):619-24.

8. European Association for Palliative Care TSG. IMPaCCT: standards for paediatric palliative care in Europe. Eur J Palliat Care. 2007;14(3):109-14.

9. NHPCO's Pediatric Standards: A Key Step in Advancing Care for America's Children [press release]. http://www.nhpco.org/quality/nhpco%E2%80%99s-standards-pediatric-care: National Hospice and Palliative Care Organization2009.

10. NHS England. E03/S/h - 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A - service specifications. https://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med-pall.pdf: NHS England., 2013.

11. Centre for Reviews and Dissemination. Systematic Reviews: CRD's guidance for undertaking reviews in health care. University of York 2008.

12. The Cochrane Collaboration. Cochrane Handbook for Systematic Reviews of Interventions. Higgins P, Green S, Ed. England Wiley-Blackwell; 2011.

13. Shamseer L, Moher D, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. Br Med J. 2015;349:g7647.

14. Popay J, Roberts H, Sowden A et al. Guidance on the conduct of narrative synthesis in systematic reviews. Lancaster: ESRC Research Methods Programme; 2006.

15. Friedrichsdorf SJ, Postier A, Dreyfus J, et al. Improved Quality of Life at End of Life Related to Home-Based Palliative Care in Children with Cancer. J Palliat Med. 2015;18(2):143-50.

16. Niswander LM, Cromwell P, Chirico J,et al. End-of-life care for children enrolled in a community-based pediatric palliative care program. J Palliat Med. 2014;17(5):589-91.

17. Sheetz MJ, Bowman MAS. Parents' Perceptions of a Pediatric Palliative Program. Am J Hosp Palliat Med. 2013;30(3):291-6.

18. Postier A, Chrastek J, Nugent S, et al. Exposure to Home-Based Pediatric Palliative and Hospice Care and Its Impact on Hospital and Emergency Care Charges at a Single Institution. J Palliat Med. 2014;17(2):183-8.

19. Fraser LK, van Laar M, Miller M, et al. Does referral to specialist paediatric palliative care services reduce hospital admissions in oncology patients at the end of life? Br J Canc. 2013;108(6):1273-9.

20. Groh G, Borasio GD, Nickolay C, et al. Specialized Pediatric Palliative Home Care: A Prospective Evaluation. J Palliat Med. 2013;16(12):1588-94.

21. Herbert A, Bradford N, Donovan L, et al. Development of a state-wide pediatric palliative care service in Australia: Referral and outcomes over two years. J Palliat Med. 2014;17(3):288-95.

22. Kassam A, Skiadaresis J, Alexander S, et al. Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. Pediatr Blood Canc. 2015;62(8):1409-13.

23. http://www.casp-uk.net/casp-tools-checklists

24. Wee B, Hadley G, Derry S. How useful are systematic reviews for informing care practice? Survey of 25 Cochrane systematic reviews. BMC Palliat Care. 2008;7(13).

25. Crocker JC, Beecham E, Kelly P, et al. Inviting parents to take part in paediatric palliative care research: A mixed-methods examination of selection bias. Palliat Med. 2015;29(3):231-40.

26. National Institute for Health and Care Excellence (NICE). NICE Guideline NG61: End of Life Care for Infants, Children and Young People. https://www.nice.org.uk/guidance/ng61. 2016.

27. Bluebond-Langner M, Beecham E, Candy B, et al. Preferred place of death for children and young people with life-limiting and life-threatening conditions: a systematic review of the literature and recommendations for future inquiry and policy. Palliat Med. 2013;27(8):705-13.

28. NHS England. Delivering the Forward View: NHS planning guidance 2016/17 - 2020/21. https://www.england.nhs.uk/wp-content/uploads/2015/12/planning-guid-16-17-20-21.pdf: 2015.

29. Coad J, Kaur J, Ashley N, et al. Exploring the perceived met and unmet need of life-limited children, young people and families. J Pediatr Nurs. 2015;30(1):45-53.

30. Wolfe J, Grier HE, Klar N, et al. Symptoms and Suffering at the End of Life in Children with Cancer. NEJM. 2000;342(5):326-33.

31. Breen M, Anderson A-K, Jones KP. Evaluation of Place of Care at Time of Death at One United Kingdom Principal Treatment Centre for Children with Cancer. Europ J Onc Nurs. 2011;15(3):277.

32. Sastry J, Ronghe M, Murphy D, et al. Nurse led palliative care at home for children with brain tumours-west of Scotland experience. Neuro-Onc. 2014;16:i109.

33. Mastro KA, Johnson JE, McElvery N, et al. The benefits of a nurse-driven patient- and family-centred pediatric palliative care program. J Nurs Admin. 2015;45(9):423-8.

34. Martinson IM, Armstrong GD, Geis DP, et al. Home Care for Children Dying of Cancer. Pediatr. 1978;62(1):106-13.

35. Junger S, Hasan C, Burger A, Garske D, Reichling S, Radbruch L, et al. Coordination of paediatric palliative home care services. Palliat Med. 2010;1):S22.

36. Van Der Tempel A, Groenenberg AP, Vallianatos S. Case management in paediatric palliative care. Arch Dis Child. 2014;99:A536-A7.

37. Academy of Medical Royal Colleges. The benefits of consultant-delivered care. . London: Academy of Medical Royal Colleges. 2012

38. National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action. http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf: 2015.

39. Morstad Boldt A, Yusuf F, Himelstein BP. Perceptions of the term palliative care. J Palliat Med. 2006;9(5):1128-36.

40. Twamley K, Craig F, Kelly P, et al. Underlying barriers to referral to paediatric palliative care services: knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom. J Child Health Care. 2014;18(1):19-30.

41. Monterosso L, Kristjanson L. Supportive and palliative care needs of families of children who die from cancer: an Australian study. Palliat Med. 2008;22(1):59-69.

Table 3: Study Characteristics:

Study	**Design & Research Questions**	**Participants**	**Intervention**	**Findings**
M. J. Sheetz et al (2012) (17)	What are parents' perceptions about whether a SPPC programme was providing key elements of paediatric palliative care? Are parents satisfied with the service? Questionnaire survey of parents whose children were receiving care from a specific SPPC programme. Salt Lake City, USA	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: MDT including pediatrician and nurse practitioner board-certified in PPM, 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% (22) of children had died at home, 53% (32) at the hospital, and 8% (5) at another hospital, 2% (1) 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.
L. K. Fraser et al (2013) (19)	What is the impact of SPPCS on the number of hospital admissions in children before their death with cancer? Retrospective cohort study of epidemiological data. Differences in hospital admission patterns were assessed using negative binomial regression Yorkshire, UK	2508 patients aged 0-19 years with cancer from 1990-2009, who were in the catchment area for the SPPCS. .	SPPC based at a children's (aged up to 35 years) hospice with a full time consultant from 2004. 24 hour 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 CNS tumours. Referral to SPPC was associated with a significantly lower rate of planned hospital admissions (IRR=0.60, 95% CI 0.43-0.85). 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 to those with leukaemia (may be due to the nature of treatment).
Groh et al (2013) (20)	Does the involvement of a SPPC team (home care) address the needs of patients and their families and thus lead to an increase in acceptance and effectiveness of SPPC? Prospective non-randomised study with two validated questionnaires; the first during the first week pf	All primary caregivers of severely ill children receiving SPPC via the PPHC team for the first time between Apr 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 pediatricians, two nurses, a social worker and a chaplain, all with special training in palliative care. 24/7 on-call.	SPPC was assoc 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 QoL and burden relief significantly increased and psychological distress and burden decreased. SPPC led to reduced rates of hospitalization and improved caregiver satisfaction with care received including psychological support and support of activities of daily living. Caregiver's felt more informed on disease situation and progression, better taken care of, improved communication with child. Psychosocial support was identified as the

	paediatric palliative home care (SPPC) service involvement, and the second a few days - six months later depending on clinical condition. Face to face by a trained psychologist. Bavaria, Germany			most helpful aspect of care. 24/7 on-call service and time for detailed conversations highly valued, as were support with practicalities e.g. ACP, equipment.
L Niswander et al. 2014 (16)	What SPPC are CYP receiving at home, and how is their end-of-life experience perceived by parents and medical personnel. Retrospective cohort review of medical notes of children who died from Dec 2004 – May 2008. New York, USA	36 children who died with a wide range of diagnoses, including cancer, enrolled in the program for a median 1.1 years before they died.	A team consisting of pediatric nurses, pediatric nurse practitioners, a pediatrician board-certified in hospice and palliative medicine, child life specialists, social workers, chaplain, and expressive therapists.	There was a median of 3 hospitalizations (inc planned), 2 emergency room visits in the last 6m 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 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 PPD. 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.
Postier et al. 2014 (18)	What is the healthcare utilization by children prior to enrollment in SPPC compared to the period after enrollment? 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 one day between 2000-2010	24/7 access and care co-ordination 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 two weeks post SPPC involvement, with a significant drop in healthcare costs. Largest decreases in resource utilization 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 (2014) (21)	What are the characteristics of the population care 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 pediatric oncology palliative care service at the RCH, and incrementally expanded over a period of 3 ½ years, commencing with a dedicated pediatrician 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 (>6m). 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%), End of life care (26%).

Friedrichsdorf (2015) (15)	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 inc QoL and location of death. Retrospective cohort survey study of bereaved parents whose children died of cancer Minneapolis, USA	Final sample of 60 bereaved parents of children who died of cancer between 2002-08 at a US tertiary paediatric institution .	PPC nurses, social workers, and chaplaincy. A PPC physician and/or pediatric 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 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.
A Kassam et al 2015 (22)	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	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.