

Appendix 3 (as supplied by the authors): Study Characteristics - full details

Article	Fraser LK et al 2013 ¹	Keele L et al 2013 ²	Dussel V et al 2009 ³
Objective	Assessed the impact of specialist pediatric palliative care services carried by a pediatric hospice	Compared demographic and clinic characteristics of patients who received palliative care consultations to those who did not	<ul style="list-style-type: none"> • Determined association of modifiable clinical factors with parental planning of LOD • Explored whether planning of the child's LOD had any impact on patterns of care and the parent's experience with child's EOL
Participants	Children who died from cancer (0-19 years), diagnosed between 1996 to 2009, and who died before Sep 2011	Children (<18 years of age), who died at hospital >5 days after admission, from all causes of death with complete administrative data on charges and hospital admissions between 2001-2011 (patients discharged < 5 days under hospice care were not included)	Children who died from cancer from 2 tertiary centres whose physicians authorized the researchers to contact the family. Deaths occurred between 1990 and 1999. Families were interviewed between 1997 and 2001
Study design	Cohort comparison	<ul style="list-style-type: none"> • Retrospective administrative database analysis • Pediatric Health Information System (PHIS) database developed by collaboration of >40 children's hospitals across the states 	<ul style="list-style-type: none"> • Retrospective cross-sectional survey of bereaved parents • Retrospective Chart review
Observation period	Referral to death	Last admission before death	Last month of life
n	497	24342	140
Data sources	<ul style="list-style-type: none"> • Secondary data base analysis • Linked data from specialist pediatric palliative care services, Register of Cancer, NHS Hospital episode statistics 	Secondary analysis of the Pediatric Health Information System including > 40 hospitals across the country	<ul style="list-style-type: none"> • Parental survey: 390 questions, partially validated, carried over the phone or in person • Patient charts
Intervention Group	Hospice Group (n=132) Patients referred to a specialist palliative care service carried by a pediatric hospice	Palliative care group (n=919) Palliative care consultation in the last admission (measured by billing code for ICD9 - PC V66.7)	Planned LOD (n=88)
Comparator	Control group (n = 311) Patients not referred to hospice services	No palliative care (n=23423) No palliative care consultation in the last admission (no billing code)	Did not plan LOD (n=52)
Setting	Residents in the Yorkshire Health Authority, UK	Children who died across > 40 US Children's Hospitals part of the Children's Hospital Association (USA) database	Dana-Farber Cancer Institute/Children's Hospital Boston, and Children's Hospitals and Clinics of Minnesota, USA
Outcomes	<ul style="list-style-type: none"> • Primary: Total number of hospital admissions • Secondary: Number of planned hospital admissions; Number of emergency hospital admissions 	Age, gender, LOS, major group category diagnostic, medications, procedures in the last admission	EOL planning, EOL support from physicians, use of home care, hospital resources utilization, place of death
Funding	Not disclosed	No external funding was received. The authors disclosed no conflict of interest	No conflict of interest was disclosed. Different sources of funding supported the authors (Agency for Health Research and Quality, National Cancer Institute, Child Health Research Grant from the Charles H. Hood Foundation, Pine Tree Apple Tennis Classic Oncology Research Fund)

Appendix 3: Study Characteristics - full details (cont.)

Article	Knapp CA et al 2009 ⁴	Arland LC et al 2013 ⁵	Postier et al 2014 ⁶
Objective	<ul style="list-style-type: none"> Described demographic characteristics, cause and LOD, and expenditure patterns of hospice users and nonusers Investigated hospice expenditure variations and characteristics of children 	Investigated relationship between changes in outcomes and an EOL program	Explored healthcare service utilization by children prior/after enrollment in home-based PPCP/hospice program carried by a tertiary care provider
Participants	Children who died in and were residents of Florida state (1-21 years) between Jul 2003 - Jun 2006 and were enrolled in the Medicaid program	Children who died of brain tumors (1 month - 19 years), with documented LOD and reason for hospital admission	Children enrolled in the home PPCP/hospice program (1 to 21 years old) for at least 1 day between 2000- 2010 (excluded children < 1 year old)
Study design	Retrospective administrative data analysis	Pre-post observational study - both periods included hospice care as part of the EOL care	Pre-post observational study
Observation period	Last year of life	<ul style="list-style-type: none"> Before standardization: 5 years After standardization: 10 years 	<ul style="list-style-type: none"> Before enrollment: 12 months After enrollment: 12 months
n	1527	114	425
Data sources/ measurement	Medicaid claims, encounter and enrollment files, death certificate	Retrospective chart review	<ul style="list-style-type: none"> Retrospective secondary data analysis Electronic medical records and accounting system for billed charges
Intervention Group	Hospice use (n= 85)	After group (n= 92 / 1996-2005) Standardized EOL care program coordinated by a hospital (comprehensive EOL discussions, medications for symptom control, primary family liaison, home visits)	Pre-PPCP
Comparator	Non-hospice use (n= 848)	Before Group (n= 22 /1990-1995) Non standardized EOL care managed by individual hospices in the geographic area (not specialized in pediatric palliative care)	Post-PPCP
Setting	Florida, USA	Children's Hospital Colorado, Colorado, USA (program implemented in 1995).	Children's Hospitals and Clinics of Minnesota's (CHC) Homecare, Pain Medicine, Palliative Care & Integrative Medicine Programs, Minnesota, USA
Outcomes measured	<ul style="list-style-type: none"> Hospice use Hospice expenditures 	<ul style="list-style-type: none"> Symptoms Hospitalizations (number and LOS) Location of death 	Change in number of hospitalizations, LOS, and total billed charges for hospital/ER stays
Funding	No conflict of interest was disclosed. Source of funding not disclosed	Did not state funding. Authors reported no conflict of interest but some of them occupied positions in Children's Hospital Colorado.	No funding was received for the research. Authors disclosed no conflict of interest. However, four authors were employees in the Department of Pain Medicine, Palliative Care & Integrative Medicine, Children's Hospitals and Clinics of Minnesota.

Appendix 3: Study Characteristics - full details (cont.)

Article	Gans D et al 2012 ⁷	Pascuet E et al 2010 ⁸	Smith A et al 2013 ⁹
Objective	Demonstrated shift in healthcare resource use and cost with the implementation of a community palliative care program	Measured differences in hospital utilization and costs with the use of respite services at a pediatric hospice	Evaluated PPCP utilization among the most costly hospitalized patients Examined factors associated with receipt of PPCP and inpatient costs.
Participants	Children living with life-threatening conditions (0 to 20 years old), enrolled in a community based pediatric palliative care program (implemented in 2010)	Children with life-limiting illnesses (age range not defined) who used 'Respite' at the pediatric Hospice at least once from May 2005 to Feb 2009	The ten percent most costly patients, in 2010, among all patients discharged from Primary Children's Medical Center (PCMC)
Study design	<ul style="list-style-type: none"> Pre-post assessment of healthcare utilization and expenditures Brief report 	Pre-Post observational study	Cohort comparison between who received PPCP and those who did not Pre-post assessment in the PPCP cohort before/after the initial palliative care consultation
Observation period	<ul style="list-style-type: none"> Before: 12 months? (2009, first and last months unclear) After: 18 months (January 2010 to September 2011) 	<ul style="list-style-type: none"> Before 1st respite: 12 months After 1st respite: 12 months 	Cohort comparison: up to 2 years Pre-post: undisclosed
n	123	66	1001
Data sources/measurement	<ul style="list-style-type: none"> Secondary analysis of claims databases (MIS/DSS claims, MEDS and CMS Net) Family quality of life and satisfaction survey 	<ul style="list-style-type: none"> Retrospective chart review Non-randomized 	Undisclosed
Intervention Group	After PPCP <ul style="list-style-type: none"> Included coordination of care and community resources, massage, art, play and music therapy Family education and training in devices operation Family counseling and bereavement, pain and symptom management, respite out of home, hospice facilities (not necessarily specialized in pediatric population) 	Before respite	PPCP Group (n=81): patients who used the program
Comparator	Before PPCP	After respite	Control Group (n= 920): patients who did not use the program
Setting	<ul style="list-style-type: none"> 11 counties in California, USA Program included several healthcare providers (home care providers, hospices and contract agencies who voluntarily participated in the program) 	<ul style="list-style-type: none"> Roger's House Pediatric Hospice (RH), Ontario, Canada Children's Hospital of Eastern Ontario (CHEO), Ontario, Canada 	Primary Children's Medical Center (PCMC), Salt Lake City, Utah, USA
Outcomes measured	<ul style="list-style-type: none"> LOS Medical Expenditures Family's quality of life and satisfaction 	<ul style="list-style-type: none"> LOS ER and Outpatient visits Overall Cost in hospital/hospice admission 	<ul style="list-style-type: none"> Cost Demographics Use of technology
Funding	Policy brief supported by Children's Hospice & Palliative Care Coalition (CHPCC) All authors belonged to UCLA University.	Funded by the Hospice	Did not state funding. First author is employed by the hospital where the research was conducted

Appendix 3: Study Characteristics - full details (cont.)

Article	Ward-Smith P et al 2008 ¹⁰	Belasco JB et al 2000 ¹¹
Objective	Compared inpatient hospital costs associated with PPCP carried by a tertiary provider	Compared cost of care at home versus at the hospital
Participants	<ul style="list-style-type: none"> • Children enrolled in the PPCP within 6 months prior to death (age range not specified) • Cases: identified within 18 months, 2 years after PPCP became fully implemented • Controls: criteria for matching not stated (potentially by diagnosis), period not specified • Exclusion criteria: children in the neonatal intensive care unit; those who died within 72 hours of initial admission; patients with incomplete medical records; and patients who enrolled in the PPCP program less than 30 days to death. 	<ul style="list-style-type: none"> • Children referred to a home based pediatric palliative care program between 1988-1992 (age bracket not specified) carried by a tertiary care provider • Applied costs from 1995 and 1996. • Of 154 patients enrolled in the PPCP during the study period, some were selected to reflect medically complicated patients whose level of care at home was comparable to being at the hospital and differed only in palliative intent rather than intent to cure.
Study design	Retrospective matched case-control	Case series
Observation period	6 months prior to death	1 day
n	18	3
Data sources/ measurement	Hospital-based charges	Retrospective chart review
Intervention Group	PPCP group (n=9) Enrolled in the Pediatric Palliative Care Program	Home care
Comparator	Non PPCP (n=9) Not enrolled in the Pediatric Palliative Care Program	Hospital care
Setting	Children's Mercy Hospital, Kansas, USA	Children's Hospital Philadelphia, Pennsylvania, USA
Outcomes measured	<ul style="list-style-type: none"> • Total hospital costs • LOS • Differences in types of procedures 	<ul style="list-style-type: none"> • Type of interventions delivered. • Place of death • Comparison of charges of care
Funding	No funding was disclosed. Authors were employees of Children's Mercy Hospital	No funding was disclosed. Authors were employees of Children's Hospital Pennsylvania.
Note: EOL = end of life, LOD = location of death, LOS = length of stay, PPCP = pediatric palliative care program.		

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