

# Pediatric Palliative Care and Inpatient Hospital Costs: A Longitudinal Cohort Study

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**abstract** **BACKGROUND:** Pediatric palliative care (PPC) improves the quality of life for children with life-limiting conditions, but the cost of care associated with PPC has not been quantified. This study examined the association between inpatient cost and receipt of PPC among high-cost inpatients.

**METHODS:** The 10% most costly inpatients treated at a children's hospital in 2010 were studied, and factors associated with receipt of PPC were determined. Among patients dying during 2010, we compared 2010 inpatient costs between PPC recipients and nonrecipients. Inpatient costs during the 2-year follow up period between PPC recipients and nonrecipients were also compared. Patients were analyzed in 2 groups: those who died and those who survived the 2-year follow-up.

**RESULTS:** Of 902 patients, 86 (10%) received PPC. Technology dependence, older age, multiple chronic conditions, PICU admission, and death in 2010 were independently associated with receipt of PPC. PPC recipients had increased inpatient costs compared with nonrecipients during 2010. Among patients who died during the 2-year follow-up, PPC recipients had significantly lower inpatient costs. Among survivors, PPC recipients had greater inpatient costs. When controlling for patient complexity, differences in inpatient costs were not significant.

**CONCLUSIONS:** The relationship of PPC to inpatient costs is complex. PPC seems to lower costs among patients approaching death. Patients selectively referred to PPC who survive most often do so with chronic serious illnesses that predispose them to remain lifelong high-resource utilizers.

**WHAT'S KNOWN ON THIS SUBJECT:** Pediatric palliative care (PPC) improves the quality of life for children with life-limiting illness and their families. The association between PPC and health care costs is unclear and has not been studied over time.

**WHAT THIS STUDY ADDS:** PPC recipients were more medically complex. Receipt of PPC was associated with lower costs when death was near but with greater costs among survivors. When controlling for medical complexity, costs did not differ significantly according to receipt of PPC.

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Pediatric palliative care (PPC) is a rapidly emerging subspecialty; currently, 69% of children's hospitals offer PPC.<sup>1</sup> PPC programs typically care for patients with life-threatening or life-shortening conditions but are not limited to end-of-life of care, as PPC involvement with a patient most often persists for periods of time lasting >1 year.<sup>2,3</sup> PPC seeks to improve the quality of life and reduce distress for patients and families of children.<sup>3</sup> It is effective at both assisting with medical decision-making and providing emotional support, not only for the child, but also for siblings and parents.<sup>4</sup> Parents report that PPC improves their children's health-related quality of life and emotional well-being.<sup>5</sup>

Whether receipt of PPC services alters health care cost is not clear. Adult palliative care reduces total inpatient costs for patients both during their terminal hospitalization and also for those discharged from hospital care compared with similar patients not receiving palliative care.<sup>6,7</sup> Receipt of pediatric hospice services in the ambulatory care setting has been associated with increased costs.<sup>8</sup>

The present retrospective cohort study was conducted to examine the association of receipt of PPC services and costs among high-cost inpatients who, although small in number, consume a disproportionate amount of inpatient resources.<sup>9,10</sup> Specifically, we compared a cohort of high-cost inpatients, defined as the top decile of patients based on inpatient costs during a calendar year, according to receipt of PPC. These patients were followed up for 2 subsequent years to examine the association between PPC and inpatient cost over time. Patients were grouped into 3 distinct categories reflecting the various types of patients cared for by PPC: (1) patients who died during or very close to their terminal hospitalization; (2) patients who died during the follow-up period; and (3) patients who survived the follow-up period.

## METHODS

We performed a retrospective cohort study of children with high inpatient costs during 2010. The study was approved by the Primary Children's Hospital (PCH) privacy board and the University of Utah's institutional review board, and it was granted a waiver for need of informed consent.

### Cohort

All patients discharged from PCH in 2010 were identified. Total 2010 inpatient cost was calculated for each patient by using the cost accounting system of Intermountain Healthcare (IH).<sup>11</sup> The top decile of patients in 2010 was included for analysis.

### Exposure

PCH's formal PPC consultation consists of an initial interdisciplinary team assessment with ongoing inpatient and outpatient follow-up. The team includes a medical director, advanced practice nurse, registered nurse, social worker, and interfaith chaplain. Referrals for PPC are made by the patient's primary inpatient team or by family request. PCH has not developed administrative predefined criteria for referrals. Consultation can be refused by the patient and family.

We identified whether patients received formal PPC consultations during their 2010 inpatient stays by using data prospectively collected by the PCH PPC team and later reviewed for accuracy by the PCH PPC medical director. A PPC consultation was defined as intervention by all or part of the interdisciplinary PPC team in which discussion of goals of care, benefits and burdens of proposed treatments, quality of life, advance care planning, code status, communication, psychosocial and spiritual distress, or symptom management were addressed. Patients who received a PPC consultation after their final discharge in 2010 were excluded from analysis.

## Data

The following 2010 data were collected for all patients in the highest inpatient cost decile using IH's enterprise data warehouse: inpatient length of stay, inpatient cost, gender, age, race, insurance status, admission to the PICU/cardiac intensive critical care unit or NICU, and use of invasive or noninvasive mechanical ventilation. For those patients previously admitted in 2009, inpatient length of stay and inpatient cost data were collected. Patients were classified as technology dependent and neurologically impaired according to predefined *International Classification of Diseases, Ninth Revision*, codes from their last 2010 admission.<sup>10,12</sup> Using previously described criteria, the number of organ systems affected by complex chronic conditions (CCCs) for each patient was established.<sup>13</sup>

All surviving patients were tracked for readmission to PCH during the subsequent 730 days after their last hospital discharge in 2010 or until they died. Almost all pediatric hospital admissions in the state of Utah are at IH facilities. Any patient who lacked IH records after discharge in 2010 was considered to be lost to follow-up, and they were excluded from the analysis.

For patients who were readmitted to PCH during the 730 days after discharge in 2010, total inpatient cost and hospital days from 2011 to 2012 were calculated by using the IH cost accounting system. We also calculated inpatient cost-per-day and determined if these patients received care in the PICU during 2011 and 2012.

Death after discharge was identified by using both inpatient and outpatient records. Records included Utah Vital Statistics, IH administrative data, and the PCH PPC program database. Patients were identified in the Utah Vital Statistics database using name, date of birth, and Social Security number.

### Analytical Framework

Inpatient cost and utilization were compared between those who received PPC consultation and those who did not receive PPC consultation in 2010 in several ways.

#### Primary Analysis: Comparisons by Survival Status

Initially, we compared 2010 total inpatient cost, length of stay, and cost-per-day for all patients in the cohort. Patients were then separated into the following 3 groups based on survival and time to death:

Group 1: Patients who died during a 2010 admission or within 10 days of discharge

Group 2: Patients who died between 11 days and 730 days after their last 2010 discharge

Group 3: Patients who survived for 730 days after their last 2010 discharge

#### Secondary Analysis: Cost-Per-Day Before and After PPC Consultation

For patients who received an initial PPC consultation during their 2010 admission, cost-per-day before and after the PPC consultation were compared. Two patients received a PPC consultation on the day of their 2010 discharge, and 5 patients received a consultation on the day before their 2010 discharge. These 7 patients received <24 hours of inpatient care after their PPC consultation and were therefore excluded from the before and after analysis. They were, however, included in the comparison over time analysis.

#### Outcomes

Cost and utilization data were compared between PPC recipients and nonrecipients by using the following outcome data:

Group 1: Patients who died during a 2010 admission or within 10 days of discharge

- Total 2010 inpatient cost (primary outcome)

- Total 2010 inpatient length of stay
- 2010 inpatient cost-per-day

Group 2: Patients who died between 11 days and 730 days after their last 2010 discharge

- Total 2011–2012 inpatient cost (primary outcome)
- Total 2011–2012 inpatient length of stay
- 2011–2012 inpatient cost-per-day
- Time to death after discharge in 2010

• Admission to the hospital during 2011–2012

• 2011–2012 admission to the PICU

Group 3: Patients who survived for 730 days after their last 2010 discharge

- Total 2011–2012 inpatient cost (primary outcome)
- Total 2011–2012 inpatient length of stay
- 2011–2012 inpatient cost-per-day
- Admission to the hospital in 2011–2012
- 2011–2012 admission to the PICU

#### Statistical Analysis

Statistical analysis was performed by using SPSS version 21.0 (IBM SPSS Statistics, IBM Corporation, Armonk, NY) and Stata version 13.1 (State Corp, College Station, TX). Mean  $\pm$  SD values were calculated for continuous data with normal distributions, and median and interquartile ranks were calculated for nonparametric data. Categorical data were compared by using  $\chi^2$  tests and relative risk (RR) ratios with 95% confidence intervals (CIs). Continuous data were compared by using either the 2-tailed Student's *t* test or the Mann-Whitney *U* test when nonparametric testing was appropriate. Factors associated with receipt of PPC were evaluated by using step-wise forward logistic regression using  $P < .05$  for addition to the model and  $P < .10$  for term removal. The adjusted odds ratio (ORs) and 95% CIs are reported.

Because patients with PPC consultations had more complex problems with more CCCs, greater use of medical technology, and greater medical use in 2009, multivariable models were developed. Covariates in the multivariate model included age, gender, race previous year total inpatient cost, neurologic impairments, technology dependence, and total number of CCCs. Multivariate comparisons in group 1 (patients who died during their 2010 admission or within 10 days) and group 3 (patients who survived 2 years of follow-up) also included CCC according to organ system category as a covariate. Multivariate comparison of group 2 (patients who died between 11 days and 730 days during follow-up) lacked enough power to include CCC according to organ system category as a covariate.

For multivariable models, a generalized linear model (GLM) with a  $\gamma$  distribution and a log link<sup>14,15</sup> was fitted for group 1. Two-part models were used for groups 2 and 3 because a significant proportion of patients incurred zero inpatient cost during the follow-up. In the 2-part model, the first component was a logit model that estimated the probability of having zero cost in the follow-up, and the second component was a GLM fitted to those patients with non-zero cost. The GLM was specified as having a  $\gamma$  distribution and a log link. The effect of PPC consultations was calculated from the combined first- and second-part models. The 2-part models were implemented by using the Stata “twopm” command. Statistical significance was set at a *P* value of <.05.

#### RESULTS

In 2010, a total of 10 034 unique patients were discharged from PCH. Of the 1003 top decile patients, 902 were included in the analysis. Eighty-nine patients were lost to follow-up, and 12 patients were excluded

because they received PPC after 2010. Ninety-eight (10.9%) patients were referred for a formal PPC consultation in 2010. Of those referred, 86 (95%) received a formal consultation (Fig 1).

PPC patients were more likely to be older, technology dependent, neurologically impaired, be admitted to the PICU (compared with the general ward), die, and have >2 CCCs (Table 1). In a multivariate logistic analysis, patients who received PPC were more likely to be technology dependent, have >2 CCCs, be admitted to the PICU, and die during 2010. Death and PICU admission in 2010 had the greatest association (OR: 11.2 [95% CI: 5.4–23.5] and 4.8 [95% CI: 1.7–13.5], respectively) with PPC (Table 2).

### 2010 Inpatient Cost and Utilization Comparison for All Patients

PPC recipients accrued significantly greater inpatient costs (median: \$138 168 vs \$90 791;  $P = .000$ ) and longer hospital stays (median: 37 vs 26 days;  $P = .002$ ) than nonrecipients in 2010. The 2010 median cost-per-day was significantly higher for PPC

recipients than for nonrecipients (median: \$3755 vs \$3404;  $P = .035$ ).

### Primary Analysis: Inpatient Cost and Utilization Comparison According to Survival Status

#### Group 1: Patients Who Died During Their 2010 Admission or Within 10 Days of Discharge ( $n = 63$ )

Among those who died during their final 2010 admission or within 10 days after discharge, median total costs and length of stay did not differ according to receipt of PPC. The median cost-per-day for PPC recipients was significantly less than for nonrecipients (median: \$4260 vs \$5945;  $P = .001$ ) (Table 3). The multivariate analysis demonstrated no significant difference in total 2010 inpatient cost between PPC recipients and nonrecipients (average total 2010 cost: \$245 214 vs \$231 072;  $P = .8$ ).

#### Group 2: Costs Among Patients Who Died During the 2-Year Follow-up Period ( $n = 45$ )

Among patients who died during the subsequent 2 years after discharge in 2010, PPC recipients were one-half as

likely to be admitted to the hospital than nonrecipients (RR: 0.5 [95% CI: 0.28–0.91]). Median total follow-up cost and length of stay over the subsequent 2 years were significantly lower for PPC recipients compared with nonrecipients. There was no statistically significant difference in inpatient cost-per-day or admission to the PICU between PPC recipients and nonrecipients during the follow-up period.

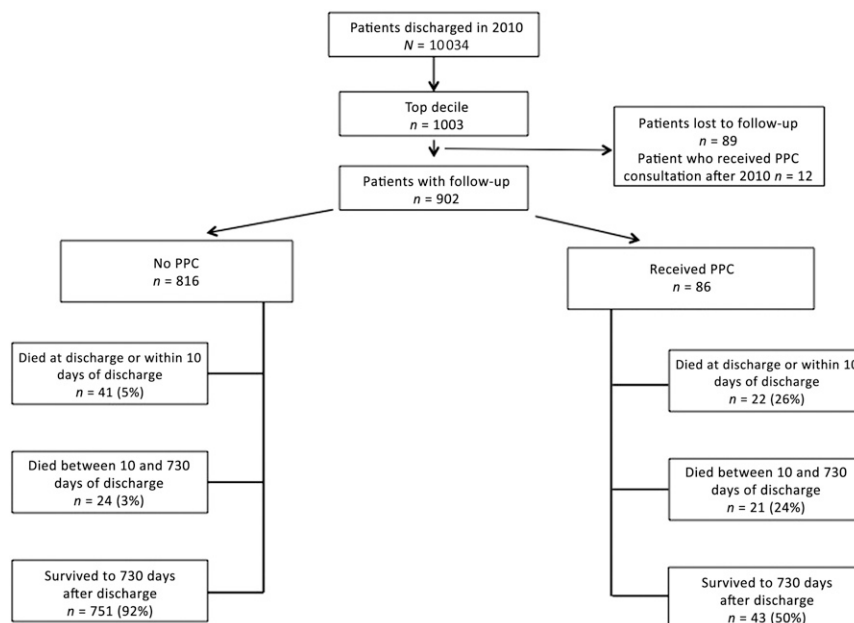
Days elapsed after 2010 hospital discharge to death was significantly less in PPC recipients than in nonrecipients (median: 140 vs 249 days). Although not statistically significant, the multivariate model and GLM demonstrated a trend that suggested PPC recipients incurred fewer total inpatient costs compared with nonrecipients during the follow-up period (average total follow-up cost: \$80 502 vs \$153 925;  $P = .4$ ).

#### Group 3: Costs Among Patients Who Survived the 2-Year Follow-up Period ( $n = 794$ )

Among those who survived the 2-year follow-up period, PPC recipients were more likely to be admitted to the hospital during follow-up compared with nonrecipients (RR: 2.1 [95% CI: 1.3–3.4]). PPC recipients also accrued statistically higher total inpatient costs and length of stay during follow-up than nonrecipients. PPC recipients had a higher cost-per-day and were more likely to be admitted to the PICU during follow-up as well. However, adjusted for differences in complexity, the multivariate model showed that total inpatient cost was not significantly different between PPC recipients and nonrecipients (average total follow-up cost: \$64 491 vs \$27 895;  $P = .06$ ).

### Secondary Outcome: Cost-Per-Day Before and After PPC consultation

Fifty-three patients received their initial PPC consultation before discharge during a 2010 admission. The cost-per-day in 2010 was significantly less costly after PPC



**FIGURE 1** Consolidated Standards of Reporting Trials diagram of the study population and patients according to survival group.

**TABLE 1** 2010 Patient Demographic Characteristics and Medical Conditions

| Variable                         | No Palliative Care |      | Palliative Care |      | P    |
|----------------------------------|--------------------|------|-----------------|------|------|
|                                  | N = 816            | %    | N = 86          | %    |      |
| Age*                             |                    |      |                 |      | .018 |
| 0–29 d                           | 175                | 21.4 | 9               | 10.5 |      |
| 30 d–23 mo                       | 248                | 30.4 | 25              | 29.1 |      |
| 3–5 y                            | 107                | 13.1 | 20              | 23.3 |      |
| 6–12 y                           | 129                | 15.8 | 18              | 20.9 |      |
| ≥13 y                            | 157                | 19.2 | 14              | 16.3 |      |
| Male gender                      | 454                | 55.6 | 40              | 47.5 | .67  |
| White race                       | 627                | 76.8 | 62              | 72.8 | .196 |
| Insurance                        |                    |      |                 |      | .061 |
| Government                       | 338                | 41.4 | 47              | 54.7 |      |
| Private                          | 469                | 57.5 | 38              | 44.2 |      |
| None                             | 9                  | 1.1  | 1               | 1.2  |      |
| Neurologically impaired*         | 326                | 40.0 | 62              | 72.1 | .000 |
| Technology dependent*            | 368                | 45.1 | 67              | 77.9 | .000 |
| >2 CCCs*                         | 235                | 28.8 | 55              | 64.0 | .000 |
| PICU admission*                  | 470                | 57.6 | 75              | 87.2 | .000 |
| NICU admission*                  | 230                | 28.2 | 13              | 15.1 | .005 |
| Invasive ventilatory support*    | 467                | 57.2 | 66              | 76.7 | .000 |
| Noninvasive ventilatory support* | 498                | 61.0 | 66              | 77.6 | .002 |
| Death*                           | 41                 | 5.0  | 22              | 25.6 | .000 |

\*P value &lt;.05.

consultation than before ( $P < .0001$ ). The median cost-per-day before PPC consultation was \$4732; after consultation, the median cost was \$3625.

## DISCUSSION

Our study identified that 1 in 10 high-cost patients received PPC. Although death during the index year was associated with receipt of PPC, only 35% of infants and children who died in the hospital received PPC. PPC consultation occurred more frequently among the highest cost patients of the top decile in the index year (ie, 2010). Our results suggest, however, that the association between receipt of PPC among high-cost inpatients and inpatient cost is

complex. Inpatient cost seemed to be linked more closely to the child's illness and proximity to death than to PPC per se. For patients who survived beyond the immediate discharge period but subsequently died, receipt of PPC was associated with decreased cost among high-cost inpatients. For PPC recipient patients who did not die, costs were increased compared with patients who did not receive PPC.

These mixed findings are likely due to the various reasons why high-cost inpatients were referred to and received PPC. Not surprisingly, we observed that patients who received PPC were more likely to die than those who did not. Proximity to death, however, is only 1 rationale of many

for providing patients with PPC. Indeed, the majority of patients who received PPC did not die during the study period. Rather than focusing only on end of life, PPC is provided to help improve the quality of life for children with serious illness that often verges on chronic critical illness. Our study found that PPC recipients had more medically complex conditions than nonrecipients. Because PPC cares for patients both near and far from death, a better description of pediatric patients who receive PPC is not simply that they have a high risk of death but also that they will likely always have significant medical needs due to their serious underlying conditions and thus are likely to be lifelong high-resource utilizers.<sup>2</sup>

Among those high-cost inpatients who died during or soon after their terminal hospitalization, we found that receipt of PPC was not consistently associated with all measures of lower costs (ie, total, length of stay) but was associated with decreased daily cost. When adjusting for complexity, receipt of PPC did not increase cost. Given that previous studies have shown that receipt of PPC enhances family satisfaction with care, the receipt of PPC is likely to be associated with increased value among high-cost inpatients who die during or soon after their terminal hospitalization.<sup>4</sup>

Our findings differ from a previous analysis of hospital administrative billing data, which examined hospital charges and receipt of PPC.<sup>16</sup> The study, which included data from >40 children's hospitals, examined hospital charges among all patients who died after 5 days during their terminal hospitalization. Although this study and the present one both reported a decrease in charge/cost-per-day among patients who received PPC, the previous study also reported a decrease in total charges and length of stay among recipients of PPC. This difference may be due to the previous

**TABLE 2** Patient Characteristics Associated With Receipt of PPC in 2010

| Variable                            | OR   | CI              |
|-------------------------------------|------|-----------------|
| Death                               | 11.2 | 5.4–23.5        |
| Hospital unit admission during 2010 |      |                 |
| Medical/surgical ward only          |      | Reference Group |
| PICU admission                      | 4.8  | 1.7–13.5        |
| NICU admission                      | 0.88 | 0.2–3.3         |
| PICU and NICU admission             | 3.2  | 0.81–12.9       |
| Technology dependence               | 3.4  | 1.8–6.6         |
| >2 CCCs                             | 2.5  | 1.5–4.2         |
| Neurologically impaired             | 1.9  | 1.1–3.4         |

**TABLE 3** Inpatient Costs and Utilization Among Patients Who Died During 2010 Admission or Within 10 d of Discharge, Patients Who Died After  $\geq 10$  Days After 2010 Discharge, and Patients Who Survived the 2-Year Follow-up

| Patient Group   | No Palliative Care                                  |                              | Palliative Care |                    | P     |
|---|---|------------------------------|-----------------|--------------------|-------|
| All patients who died during 2010 admission or within days of discharge                   | N = 41  |                              | N = 22          |                    |       |
|   | Median  | Interquartile                | Median          | Interquartile      |       |
|   | Total cost 2010                                     | \$165 839 \$84 689/\$347 314 | 166 059         | \$79 245/\$307 346 | .897  |
|   | LOS 2010  | 22.4 d 14.3/55 d             | 36.8 d          | 18.7/64.3 d        | .121  |
| Cost/day 2010   | \$5945 \$4735/\$8940                                | \$4260                       | \$3071/\$5663   | .001               |       |
| Subsequent inpatient costs in patients who died after $\geq 10$ days after 2010 discharge | N = 24  |                              | N = 21          |                    |       |
|   | Median  | Interquartile                | Median          | Interquartile      |       |
|   | Total cost 2011–2012                                | \$48 733 \$9621/\$297 189    | \$0             | \$0/\$96 293       | .019  |
|   | LOS 2011–2012                                       | 11.9 d 3.6/61.2 d            | 0 d             | 0/26.1 d           | .010  |
|   | Cost/day 2011–2012                                  | \$3487 \$2452/\$4596         | \$0             | \$0/\$4834         | .075  |
|   | Time to death                                       | 259 d 179/517 d              | 140 d           | 34/403 d           | .029  |
|   |   | N %                          | N %             |                    |       |
|   | Hospital admission 2011–2012                        | 19 79.2                      | 10 47.6         |                    | .027  |
|   | PICU admission 2011–2012                            | 14 56                        | 8 40            |                    | .218  |
|   | Subsequent inpatient costs in patients who survived | N = 751                      |                 | N = 43             |       |
| Median  |   | Interquartile                | Median          | Interquartile      |       |
| Total cost 2011–2012  |   | \$0 \$0/\$21 081             | \$33 992        | \$0/\$93 280       | <.001 |
| LOS 2011–2012   |   | 0 d 0/6.0 d                  | 9.1 d           | 0/31.4 d           | <.001 |
| Cost/day 2011–2012  |   | \$0 \$0/\$2956               | \$2965          | \$0/\$4295         | <.001 |
|   |   | N %                          | N %             |                    |       |
| Hospital admission 2011–2012  |   | 317 42.2                     | 31 72.1         |                    | <.001 |
| PICU admission 2011–2012  |   | 127 16.9                     | 20 46.5         |                    | <.001 |

LOS, length of stay.

study's reliance on billing data to discern patient exposure to PPC (whereas in our study, the electronic medical record was used to document receipt of PPC services) or due to the fact that our study evaluated only patients within the upper decile costs in 2010.

The present study is the first to examine the association of inpatient cost and receipt of PPC over time among high-cost inpatients. Because our hospital system uses a detailed cost accounting system, we were able to present costs rather than charges. Among children who survived over the 2-year follow-up period, patients who received PPC accrued more costs and had more inpatient days than nonrecipients in the subsequent 2 years. PPC recipients seemed to be more medically complex compared

with nonrecipients, which likely accounts for this increase in cost, as we found no difference in cost when controlling for complexity and other factors. Among those patients who died during the subsequent 2 years of follow-up, PPC recipients had less total inpatient costs and hospital days. However, statistical significance did not persist in the adjusted model, which might be related to small study number.

Our findings are limited by several factors. First, our results were based on retrospective, administrative data from a single institution, and PPC practices vary by hospital. Second, patient cost could be associated with receipt of PPC (due to patients with chronic critical illnesses being selectively referred for PPC). To minimize this potential bias, we

intentionally limited our analysis to only high-cost inpatients. Our findings regarding inpatient costs, time to death, and PPC among very high-cost inpatients cannot be reliably generalized to all pediatric inpatients with life-threatening or life-shortening conditions. Finally, although we excluded patients lost to follow-up, we were unable to include inpatient costs associated with patients who sought inpatient care outside Utah and also continued to seek care at PCH.

## CONCLUSIONS

As escalating health care costs continue to cause concern, policy makers and health care providers are examining various solutions to increase the value of health care. One option often explored is palliative

care. Previous research has shown that PPC improves quality.<sup>4,5</sup> Our findings suggest that among children who have experienced substantial

previous inpatient care, health care which emphasizes quality of life does not increase cost and may cost less when children are close to death.

Thus, an argument can be made that PPC can increase the value of inpatient health care among high-cost inpatients.

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