



Supporting Children at End of Life: The *Many* Benefits of Pediatric Palliative Care

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Abstract:

- **Background:** Terminally ill pediatric patients present a complex clinical challenge due to the multifactorial nature of their pain and suffering at end of life, in addition to the grief experienced by the family. Pediatric specific palliative care programs can help support families and patients cope with the progression of the disease by treating the patient's physical symptoms and also their emotional, spiritual, and psychosocial distress as they transition toward death.
- **Methods:** Research studies demonstrating the effects of palliative care on terminally ill pediatric patients and their families were identified using a systematic search of two databases. The articles were reviewed and assessed for statistical significance.
- **Results:** The literature search resulted in 98 articles, 8 of which were selected for inclusion in the final review. The results of the studies selected revealed that palliative care programs had statistically significant positive effects on the management of parental grief, patient symptoms such as dyspnea, anxiety and pain, and communication between the family and the care team. Study results also showed decreased health care costs, lower chances of a patient dying in the PICU, and reduced provider guilt when patients were referred to palliative care.
- **Conclusions:** Utilization of pediatric palliative care programs for terminally ill patients has multiple benefits and can increase the quality of life for the patient and the family. Continued research should be conducted to quantify advantages of these programs with the goal of increasing access and expanding the professional field of pediatric palliative care.



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Background

- Approximately 53,000 children die every year from illness, extreme prematurity, inheritable disorders or lethal congenital conditions
- Families experience unique pain, trauma and grief when losing a child to a terminal illness
- Psychological and emotional distress are increased in families who lose a child versus an adult family member due to the nature of the parent-child relationship
- Pediatric patients require specialized medical treatment during their illness but also have specific needs at end of life which differ from adult patients
- Pediatric palliative care programs provide interdisciplinary support to both the patient and their family to ease physical, emotional, psychosocial and spiritual pain
- Palliative care is a term which may be associated with end of life by both providers and patients, but is most beneficial when started at the diagnosis of a terminal or chronic illness according to the American Academy of Pediatrics recommendation

Objective

- The purpose of this review is to examine the benefits of pediatric palliative care with regard to symptom management, emotional support of the patient and family, ICU admissions at end of life, and health care costs

Methods

- 4 databases searched: PubMed, Embase, CINAHL, Cochrane Library
- Search terms included
 - Pediatric AND end of life
 - Pediatric AND palliative care
 - Pediatric and hospice
 - Pediatric AND palliative care AND referral
 - Pediatric AND palliative care AND Cancer
 - Pediatric AND palliative care AND symptom management

- Date range set to 2014-2019
- Articles were selected based on thematic congruence with the research question
- Titles were first reviewed for appropriateness, followed by abstracts
- Inclusion criteria: articles which addressed beneficial aspects of pediatric palliative or hospice care programs
- Exclusion criteria: Articles which did not specifically address pediatric patients, articles which did not focus on benefits of these programs to patients and their families
- Study quality appraised using Cochrane risk of bias assessment
- Data extracted and outcomes synthesized by group

Results

- A total of 94 articles were retrieved using the above search methods
- Of these 94, 9 were selected for use in the study
- 2 retrospective cross-sectional studies, 5 retrospective cohort studies, 2 systematic reviews, and 1 clinical update article.

Benefits of Referral to Palliative Care for Pediatric Patients				
Study	Multisite (Yes/No)	Sample Size	Study Duration	Study Findings
Gans et al., 2016	No	132	3 years	<ul style="list-style-type: none"> • 50% reduction in inpatient stays • Inpatient costs reduced by \$3331 per patient
Geest et al., 2014	No	123	4 years	<ul style="list-style-type: none"> • Improved management of long term parental grief correlated with management of pain (B = 6.60 95% CI [2.45, 10.75] P <0.01) , anger (B = 4.90 95% CI [2.33, 7.46] P <0.0) anxiety to be left alone (B = 4.52 95% CI [2.06, 6.99] P <0.01) anxiety about the future (B = 5.02 95% CI [1.62, 8.43] P<0.01) and severity of dyspnea (B = 2.96 95% CI [0.07, 5.85] P<0.05)
Kaye et al., 2017	No	321	4 years	<ul style="list-style-type: none"> • Referrals <30 days before death = OR: 4.7, 95% CI: 2.47–8.97, P<0.0001 increased chance of death in the PICU vs non-PICU
Madden et al., 2015	No	45	18 years	<ul style="list-style-type: none"> • Reduction of health care costs by \$3430.36 per patient • Reduction of caregiver burden
Ranallo, L., 2017	N/A	N/A	N/A	<ul style="list-style-type: none"> • Improved symptom management • Improved communication with the care team, • Improved patient advocacy • Increased parental acceptance of end of life care • Reduced provider guilt.
Rosfield et al., 2019	No	777	2 years	<ul style="list-style-type: none"> • 79% less likely to be admitted to the ICU odds ratio [OR] = 0.21; 95% confidence interval
Thrane et al, 2017	No	265	4 years	<ul style="list-style-type: none"> • Lower pain scores post-referral: (t(47) = 1.816, p < 0.05 one tailed).
Vollenbruch et al., 2015	No	38	3 years	<ul style="list-style-type: none"> • Parental and health care team concordance in symptom severity assessment correlated with improved parental quality of life (p = 0.041) and satisfaction with care (p = 0.037).
Weaver et al., 2015	N/A	73	20 years	<ul style="list-style-type: none"> • Improved symptom management • Encouragement of family centered communication • Facilitation of informed advanced care planning • Family support during times of transition.

Summary

- Findings suggest a positive correlation between referrals to pediatric palliative care and improvement of physical symptoms such as pain, nausea and dyspnea
- Management of patient symptoms was shown to decrease psychosocial and emotional distress of the parents and the family members, and reduced provider guilt
- Palliative care has been shown to improve communication between the patient, medical team, and caregivers which improves parental satisfaction with patient care
- Palliative care supports family during times of transition and helps support care at home, thereby reducing ICU admissions
- Enrollment in palliative care reduces length of inpatient stays, and reduces health care costs
- Enrollment facilitates advanced care planning and definition of goals of care

Conclusion

- Enrollment in palliative care should be considered at the point of diagnosis for pediatric patients with a terminal illness
- The literature demonstrates multiple benefits of palliative care including symptom management, emotional and psychosocial support of the patient and family, and reduction in health care costs

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