

Date published/posted: July 14, 2009

Evidenced Based Benefits of Palliative Care Programs on Patient/Family Quality of Life

In planning to evaluate the program's impact on patients and families quality of life, the existing evidence was examined.

Clinical Question

P (population/problem)	Among children with life-limiting illnesses
I (intervention)	does the use of a palliative care program
C (comparison)	compared with not using a palliative care program
O (outcome)	improve quality of life for patients and their families?

Definitions:

Pediatric palliative care is a philosophy and an organized program. The program includes, but not limited to, pain management, grief and family counseling, child life intervention, music therapy, peer support, spiritual support, holistic health, community resource education, and appropriate respite care. It serves children with life-threatening conditions, regardless of life expectancy, and their families, from point of diagnosis, with hopes for a cure, throughout the course of illness, to end of life care, including hospice and the bereavement process. There are three distinct populations of children who stand to benefit from improvements in palliative care. The first group are those who are born without an expectation of survival to adulthood but may live a long time with substantial suffering, i.e. neurodegenerative illnesses. The second group are those who acquire a life threatening illness, such as cancer. The last group are those who suffer relatively sudden death due to trauma. The purpose of palliative care is to enhance quality of life for the *child* and *family* by minimizing suffering, optimizing function, and providing opportunities for personal growth. (Cincinnati Children's Hospital Medical Center 2009)

Quality of life is an overall perception of well being by the individual or group of people regarding the ability to pursue daily activities, not only physically, but also emotionally, socially, and spiritually.

Health Related Quality of Life (HRQoL) constructs for the pediatric population (ages 2-18 years) are physical health and psychosocial health which includes emotional functioning, social functioning, and school functioning as measured by the PedsQL 4.0 Generic Core Scales.

Health Related Quality of Life (HRQoL) constructs for adults are physical health, which includes physical functioning, role-physical, bodily pain, and general health, and psychosocial health, which includes vitality, social functioning, role-emotional, and mental health as measured by the SF-36 health survey scales.

Target Population: Children with life-limiting illnesses and adults with a childhood life-limiting illness and their families

Recommendation

It is recommended that clinicians offer patients with life-limiting illnesses and their families palliative care services (see definition above) to improve quality of life in areas of mental and emotional health. (Wolfe 2008[4a], Hays 2007[4a], and Ringdal 2004[4a])

Discussion/summary of evidence

Seven studies were found. The Seattle Project (Hays et al 2006 [Level 4a]) looked at their pediatric palliative care program and its effects on patient quality of life and on family satisfaction, using a longitudinal study design. It reported a statistically significant improvement in the emotional domain on a pediatric health related quality of life tool.

Inger, Ringdal et al, 2004 [Level 4a], also used a longitudinal design to study HRQoL in adult patients with terminal illnesses and their family members who participated in palliative care services in Norway and Sweden. It showed statistically significant positive results in the domains of emotional and mental health.

Similarly, the study by Wolfe et al, 2008 [Level 4a], indirectly assessed HRQoL issues. Surveys over time of family members of deceased children who had received palliative care services and retrospective chart reviews concluded that those services resulted in less suffering for the children and a greater sense of preparedness for the family.

A lesser quality systematic review on effectiveness of palliative care done by Zimmermann et al, 2008 [Level 1b], lacked statistical power in regards to HRQoL domains.

The two part study from Australia (Monterosso et al 2007 & 2008 [Levels 4a & 4b, respectively]) which used qualitative and quantitative methods to seek feedback from parents of dying children, revealed areas which parents considered important. The main themes were similar to parents' voices in California as reflected in the assessment of the perceptions of parents of deceased pediatric patients who received palliative care (Contro et al 2002 [Level 4b]). Common themes were: 1. Both parents and health care workers need a better understanding of the concepts of palliative care. 2. Parents want clear, honest information communicated compassionately about their child's condition and prognosis. 3. Parents want practical nutrition and pain management, support for siblings and consistent guidance with community resources regarding insurance, respite, and follow up bereavement care.

The National Association of Children's Hospital and Related Institutions (NACHRI) listserv had two institutions that responded. They both shared that they have a hospital based pediatric palliative care program but no evaluation of the program currently.

The grade for this body of evidence is moderate.

Health Benefits

One study reported findings that parents, who used palliative care services, perceived their children to be experiencing less suffering from anxiety, dyspnea, fatigue, and pain. It also reported that parents felt more prepared for the circumstances surrounding the patients' last months of life and at the time of death. (Wolfe et al, 2008 [Level 4a])

References/citations

Cincinnati Children's Hospital Medical Center. Pediatric palliative and comfort care team. Retrieved

7/9/2009 <http://www.cincinnatichildrens.org/svc/alpha/p/pact/default.htm>

Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics & Adolescent Medicine*, 156(1), 14-19. [Level 4b]

Hays, R. M., Valentine, J., Haynes, G., Geyer, J. R., Villareale, N., McKinstry, B., et al. (2006). The Seattle pediatric palliative care project: Effects on family satisfaction and health-related quality of life. *Journal of Palliative Medicine*, 9(3), 716-728. [Level 4a]

Inger Ringdal, G., Ringdal, K., Jordhøy, M. S., Ahlner-Elmqvist, M., Jannert, M., & Kaasa, S. (2004). Health-related quality of life (HRQOL) in family members of cancer victims: Results from a longitudinal intervention study in Norway and Sweden. *Palliative Medicine*, 18(2; 2), 108-120. [Level 4a]

Monterosso, L., & Kristjanson, L. J. (2008). Supportive and palliative care needs of families of children who die from cancer: An Australian study. *Palliative Medicine*, 22(1), 59-69. [Level 4b]

Monterosso, L., Kristjanson, L. J., Aoun, S., & Phillips, M. B. (2007). Supportive and palliative care needs of families of children with life-threatening illnesses in western Australia: Evidence to guide the development of a palliative care service. *Palliative Medicine*, 21(8), 689-696. [Level 4a]

Wolfe, J., Hammel, J. F., Edwards, K. E., Duncan, J., Comeau, M., Breyer, J., et al. (2008). Easing of suffering in children with cancer at the end of life: Is care changing? *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 26(10), 1717-1723. [Level 4a]

Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., & Tannock, I. (2008). Effectiveness of specialized palliative care: A systematic review. *JAMA : The Journal of the American Medical Association*, 299(14), 1698-1709. [Level 1b]

Note: Full tables of evidence grading system available in separate document:

- [Table of Evidence Levels of Individual Studies by Domain, Study Design, & Quality](#) (abbreviated table below)
- [Grading a Body of Evidence to Answer a Clinical Question](#)
- [Judging the Strength of a Recommendation](#) (abbreviated table below)

Table of Evidence Levels (see note above)

<i>Quality level</i>	<i>Definition</i>
1a† or 1b†	Systematic review, meta-analysis, or meta-synthesis of multiple studies
2a or 2b	Best study design for domain
3a or 3b	Fair study design for domain
4a or 4b	Weak study design for domain
5	Other: General review, expert opinion, case report, consensus report, or guideline

†a = good quality study; b = lesser quality study

Table of Recommendation Strength (see note above)

<i>Strength</i>	<i>Definition</i>
“Strongly recommended”	There is consensus that benefits clearly outweigh risks and burdens (or visa-versa for negative recommendations).
“Recommended”	There is consensus that benefits are closely balanced with risks and burdens.
No recommendation made	There is lack of consensus to direct development of a recommendation.

Dimensions: In determining the strength of a recommendation, the development group makes a considered judgment in a consensus process that incorporates critically appraised evidence, clinical experience, and other dimensions as listed below.

1. Grade of the Body of Evidence (see note above)
2. Safety / Harm
3. Health benefit to patient (*direct benefit*)
4. Burden to patient of adherence to recommendation (*cost, hassle, discomfort, pain, motivation, ability to adhere, time*)
5. Cost-effectiveness to healthcare system (*balance of cost / savings of resources, staff time, and supplies based on published studies or onsite analysis*)
6. Directness (*the extent to which the body of evidence directly answers the clinical question [population/problem, intervention, comparison, outcome]*)
7. Impact on morbidity/mortality or quality of life

Supporting information

Introductory/background information

Palliative care is a relatively new development in the pediatric population. Pediatric institutions around the country are developing palliative care programs and are offering palliative care services along side traditional curative treatments. Within our Midwestern community, our institution’s program has been providing palliative care services, including hospice and end of life care, in the home for over ten years to children with life limiting illnesses and their families

Group/team members

Group/Team Leader: Lucy O’Quinn BSN,RN, CPN, Clinical Care Coordinator for StarShine Hospice
e-mail address lucy.oquinn@cchmc.org

Other group/team members: Barbara Giambra, MS, RN, CPNP, Evidence-Based Practice Mentor

Search strategy

1. DATABASES

- OVID MEDLINE OVID CINAHL
 OVID EBM Reviews (Cochrane) PubMed Clinical Queries
 other (specify)

NACHRI List serve: Inquiry included if they have a pediatric palliative care program, what type of patients they serve, what type of services are provided and if there is an evaluation program.

2. SEARCH TERMS (and Boolean combinations, if any).

Pediatric; palliative care, quality of life, life limiting illness, and evidence based

Known conflicts of interest: *none*

Copies of this Best Evidence Statement (BEST) are available online and may be distributed by any organization for the global purpose of improving child health outcomes. Website address: <http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/default.htm>

Examples of approved uses of the BEST include the following:

- copies may be provided to anyone involved in the organization's process for developing and implementing evidence based care;
- hyperlinks to the CCHMC website may be placed on the organization's website;
- the BEST may be adopted or adapted for use within the organization, provided that CCHMC receives appropriate attribution on all written or electronic documents; and
- copies may be provided to patients and the clinicians who manage their care.

Notification of CCHMC at HPCEInfo@cchmc.org for any BEST adopted, adapted, implemented or hyperlinked by the organization is appreciated.

Additionally for more information about CCHMC Best Evidence Statements and the development process, contact the Center for Professional Excellence/Research and Evidence-based Practice office at CPE-EBP-Group@chmcc.org

Note

This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.

Reviewed by Clinical Effectiveness