

Pediatric Palliative Care
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Pediatric patients with terminal illnesses frequently lose continuity of care in the early stages of the illness. Providing a palliative care program early in the illness, before the patient is eligible for hospice care may help to meet the complex needs and provide more consistent care to these patients. This presentation will discuss the development, implementation and evaluation of a palliative care program in a children's medical center in the southwestern United States.

Problem

Lacking continuity of care during the stages of death and dying with children is addressed, in comparison to hospice, with the desire to implement a multidisciplinary palliative care team to effect continuity of care through to end of life.

Evidence

Leaders in palliative care have called for a comprehensive approach to palliative care for seriously ill children, which would begin well before the child is imminently dying and would be integrated with other treatment modalities earlier in the disease trajectory (Rushton and Catlin, 2002). Staff members, in all occupations, report feeling inexperienced, with feelings of distress and inadequacy in their communications with patients and families (Contro et.al, 2004). Education of healthcare professionals in Palliative Care and instituting the model would provide needed relief to patients, families and healthcare workers.

Strategy

Develop educational tools and guidelines for the Palliative care program based on the recommendations of the Initiative for Pediatric Palliative Care's peer-reviewed

curriculum and the National Guideline Clearinghouse's (2001) ten most important needs of families of dying patients.

Practice Change

Advanced Practice Nurses often play clinical leadership roles on palliative care teams, as well as acting as clinical consultants, program administrators, educators and researchers (Meier and Beresford, 2006). See Pediatric Palliative Care Organizational Chart.

Evaluation

See Palliative Care Patient Satisfaction Survey.

Results

Once the palliative care program is implemented, the surveys are received and scores totaled, the outcome measures will be addressed in six month increments. Scores from the surveys will determine changes to lacking areas of the program and will be reviewed by the members of the Palliative Care Team for implementation.

Recommendations

See Pediatric Palliative Care Organizational Chart

References:

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Palliative Care Patient Satisfaction Survey

A=Rarely B= Sometimes C=Almost Always D=Always E=Doesn't apply

1. ____ The nursing and medical staff was timely and attentive in addressing your loved ones' pain needs.
2. ____ There was adequate staff to meet the needs of the family (Child Life, LMSW, Chaplain, Psychiatry, Nursing and Medical Services) during terminal illness and aftercare.
3. ____ Change in condition information was relayed to the patient and family in an appropriate and timely manner.
4. ____ Family's spiritual and cultural needs were respected during the duration of palliative care.
5. ____ The palliative care team assessed and responded to your needs during bereavement.

Pediatric Palliative Care Organizational Chart

