

How children die in hospital.

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Abstract:

A retrospective analysis was performed to describe the course of terminal care provided to dying hospitalized children in terms of symptom assessment and management, and communication and decision-making, at the end of life. Seventy-seven of 236 infants and children who died after hospital admission in Edmonton, Canada between January 1996 and June 1998 met entry criteria. Only children who died after a minimum hospitalization of 24 hours in the case of chronic illness or after a minimum hospitalization of seven days following an acute event were included. Unanticipated deaths were excluded. Eighty-three percent of children died in intensive care settings (64/77), and 78% (60/77) were intubated prior to their death. Symptoms were recorded in narrative progress notes. Five of 77 (6%) charts contained specific pain assessment and treatment records. Opioid analgesia was provided in 84% of all cases (65/77). Six (8%) patients had do not resuscitate (DNR) orders preceding final hospital admission and 56/71 (79%) remaining patients had documented discussion resulting in DNR decision during final hospital admission. Median time from DNR to death was < one day. Mode of death was withdrawal of therapy in 33/77 (43%), no cardiopulmonary resuscitation (CPR) in 26/77 (34%), and failed CPR in 13/77 (17%). Five children were declared brain dead. In only one case was there evidence in the medical record of the possibility of death being discussed explicitly with the patient. Decision-making regarding end-of-life issues in this pediatric population was deferred very close to the time of death, and only after no remaining curative therapy was available. Acuity of care was very high prior to death. Children are rarely told that they are dying.

Comments:

Strengths/uniqueness: Given the limited research on palliative care in children, this retrospective study provides useful information regarding the problems associated with this patient population.

Weakness: A chart review is always hampered by the uncertainty of completeness of the available records. There is limited discussion of how the authors see this information as furthering our knowledge, or how they plan to use this information for program development or further research.

Relevance to Palliative Care: Provides an incentive to research in this under serviced palliative care population, and further discussion on program planning.