

End-of-life care at hospitals varies for children with cancer

February 5 2009

Though treatment of pain and attention to end-of-life care for pediatric cancer patients has improved over the last few decades, there is still work to be done. Additionally, opioid prescriptions for pediatric cancer patients while hospitalized during the last week of life vary greatly among hospitals. These were the findings of a study and editorial published in *Pediatric Blood & Cancer*.

Cancer is the leading cause of death by disease in children between the ages of 1 and 19. Children with terminal cancer commonly receive pain medication. The chances that a child with cancer who dies in a hospital will receive this medication, commonly an opioid drug, may depend on which hospital is treating the child.

Using detailed data from the Pediatric Health Information System, the investigators examined the cases of 1,466 subjects 24 years of age and under who were treated at 33 hospitals at time of death between 2001 and 2005. They found that only 56 percent received opioids every day during the hospitalized portion of their last week of life. Substantial variation was found across children's hospitals, ranging from 0 to 90.5 percent of eligible patients at a given hospital receiving daily opioid therapy.

Patients with private insurance received daily opioids 63.4 percent of the time, compared to 52 percent for those with Medicaid or other government coverage. Age and diagnosis also played a role: patients aged 10-19 years were more likely to receive daily opioids (61 percent) than

those who were younger or older; and patients with brain tumors were less likely than those with other forms of cancer, such as leukemia/lymphoma, to receive daily therapy.

Multiple factors may contribute to the manner in which opioids are used within a particular hospital, including: the prevailing medical culture, attitudes towards death and the care of dying patients, the lingering stigma associated with opioids, the potential influence of clinicians with special interests in end-of-life care and the availability of hospice and other community resources.

The number of children with cancer who die in pain is unknown, though parent interview studies have revealed that pain management skills by pediatric oncologists may need further improvement.

Many parents report that the suffering of children dying from cancer was not adequately relieved and identify pain as a prominent concern. Additionally, a number of attending physicians, residents and nurses have reported that they feel inexperienced in pain management.

Regardless of the precise reasons, the existence of substantial variation among hospitals in pediatric EOL care practices strongly suggests that interventions to alter these practices will be most effective if they are adapted to the specific social, cultural, technical and institutional configuration of each hospital.

"The findings demonstrate how useful it would be to have indicators to measure the quality of pediatric end-of-life care and enable comparisons across hospitals. Interventions to improve practices in pediatric end-of-life care may be most effective if adapted individually to each hospital," says Andrea D. Orsey, M.D., M.S.C.E., co-author of the study.

According to Sarah Friebert, M.D., author of a related editorial on the

subject, "As the field of pediatric palliative care expands, future studies should focus on monitoring quality indicators across time and diverse settings."

Many barriers to adequate pain management exist. In resource-rich countries where opioid availability is not a factor, a few of the reasons for inadequate pain management in the pediatric oncology population include: difficulties in assessing young children, poor training in pain management, fear of opioid addiction and the unwillingness of children or parents to acknowledge pain for fear of what it signifies (recurrent/relapsed disease, necessary hospital visits and death).

"Despite these and other obstacles, good pain management seems to be the least we can do for our pediatric patients with cancer," says Friebert. "In addition to comprising good, holistic pediatric care, adequate pain management improves ability to cope with therapy (both physically and psychologically), improves nutrition and sleep and facilitates healing."

"Importantly, for those for whom the journey of cancer will not end in cure, relief of distress from pain at the end of life carries long-lasting implications for bereaved parents, who cope much better when their dying children's pain is well controlled," says Friebert.

Source: Wiley

Citation: End-of-life care at hospitals varies for children with cancer (2009, February 5)
retrieved 23 April 2024 from

<https://medicalxpress.com/news/2009-02-end-of-life-hospitals-varies-children-cancer.html>

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