

Hospital care for children and young adults in the last year of life: a population-based study

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BACKGROUND: To help design population-based pediatric palliative care services, we sought to describe the hospital care received in the last year of life by children and young adults who died. We also determined the proportion with complex chronic conditions (CCCs) and tested whether the use of hospital services increased as the date of death drew nearer.

METHODS: For all deaths occurring under 25 years of age from 1990 to 1996 in Washington State, USA, we linked death certificate information to hospital utilization records and analyzed the timing and duration of hospitalizations and the nature of hospital procedures during the year prior to death.

RESULTS: Of the 8 893 deaths, 25 % had CCCs. Among infants with CCCs, 84 % were hospitalized at the time of death and 50 % had been mechanically ventilated during their terminal admission. Among the 458 CCC neonates dying under a week of age, 92% of all days of life were spent in the hospital; among the 172 CCC neonates dying during the second to fourth weeks of life, 85 % of all days of life were spent hospitalized; among the 286 CCC infants dying during the second to twelfth month of life, 41 % of all days of life were spent hospitalized. Among children and young adults with CCCs, 55 % were hospitalized at the time of death, and 19 % had been mechanically ventilated during their terminal admission. For these older patients, the median number of days spent in the hospital during the year preceding death was 18, yet less than a third of this group was hospitalized at any point in time until the last week of their lives. The rate of hospital use increased as death drew near. For subjects who had received hospital care, 44 % had governmental insurance as the source of primary payment.

CONCLUSIONS: Infants who died spent a substantial proportion of their lives in hospitals, whereas children and adolescents who died from CCCs predominantly lived outside of the hospital during the last year of life. To serve these patients, pediatric palliative and end-of-life care will have to be provided in an integrated, coordinated manner both in hospitals and home communities.

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Authors:

Feudtner C, DiGiuseppe DL, Neff JM

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