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Trends in Place of Death in Children who died after discharge from Paediatric Intensive Care Units : A national data linkage study

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Aim

To identify characteristics of children who died in the community rather than hospital.

Conclusion

A large proportion of children dying after discharge from PICU continue to die in hospital. More involvement of palliative care at the point of discharge has the potential to offer choice around place of care and death for these children and families.

Methods

All children admitted to a PICU in England or Wales (1st Jan 2004 and 31st Dec 2014) were identified in the PICANet dataset. Linkage to death certificate data was available up to the end of 2014.

Place of death was categorised as hospital (hospital or PICU) or community (hospice, home or other) for multivariable logistic modelling.

Results

The cohort consisted of 110,328 individuals. 4760 deaths occurred on first admission in PICU (excluded from analyses) and 7709 deaths occurred after first discharge from PICU. Overall 41.2% of these deaths occurred in hospital, 32.5% in PICU, 16.6% at home, 8.7% in hospice and 0.7% elsewhere. Deaths in hospital (incl PICU) decreased from more 83.8% in 2004 to 68.1% in 2014. 852 (0.8%) of children were discharged to palliative care.

Children discharged to palliative care were 8.4 times more likely to die in the community (OR 8.36 95%CI (6.76-10.34)). Children in all older age groups were significantly more likely to die outside hospital than the under 1s.

Children from a South Asian background (OR 0.48 95%CI (0.36-0.58)) and those living in the most deprived categories were significantly less likely to die outside the hospital.

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