

Outcomes in Paediatric Intensive Care Units for Children with Life-Limiting Conditions: A national data linkage study

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Objective

To identify children with a Life-Limiting Condition (LLC) who have had an admission to a Paediatric Intensive Care Unit (PICU) in England and their outcomes.

Approach

Data for all children who had had a PICU admission in the UK between 1st Jan 2004 and 31st March 2015 were identified from the PICANet dataset. Linkage to inpatient Hospital Episode Statistics (HES) data was undertaken by the NHS Health and Social Care Information Centre for all children who had been resident in England. Their standard algorithm using NHS number, date of birth, sex and postcode was used. All inpatient HES episodes from the financial years 1997/98-2014/15 were received.

Although the data quality is high in the PICANet dataset, comorbidities are variably coded therefore identifying whether a child has a LLC or not is not possible. A previously developed ICD10 coding framework was used to identify individuals with one or more of these LLC codes in the inpatient HES dataset.

Results

A total of 199,548 PICU admissions in the UK for 135,759 individuals occurred during the time period of the study. Data for 43,565 admissions (32,025 individuals) were excluded due to not having been resident in England or poor quality demographic data.

Data on 103,734 individuals (155,983 admissions) were sent for linkage. Successful linkage occurred in 102,722 individuals (99.4%). Individuals who could not be linked were excluded from the analysis.

51.0% of these children had a LLC and these children accounted for 62.7% of the PICU admissions.

The crude PICU death rate in the children with a LLC was 5.0% (n=4826) compared to 3.1% (n=1786) in those without a LLC. The OR of death in a model adjusted for diagnostic group, sex, age, and expected risk of mortality for children with a LLC was 2.11 (95%CI 1.97-2.27).

Conclusion

Children with a LLC account for a large proportion of all PICU admissions in England. Although only one in twenty of these children die in PICU, as death may be expected in this population of children more integration of specialist palliative care with PICU services may allow more choice for children and families.

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