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Effect of sampling period on the numbers of children and young people with a life limiting condition in stable, unstable, deteriorating and dying stages

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Objective

To determine stage of condition (stable, unstable, deteriorating or dying) for children and young people (CYP) aged 0-25 years in Scotland with a life limiting condition (LLC) and to analyse the effects of different sampling periods on estimates of CYP in each group.

Approach

A national cohort of 20436 CYP with a LLC, resident in Scotland between 1 April 2009 and 30 March 2014, was identified from linked routinely collected healthcare data. Stage of condition was determined using the Scottish Morbidity Record (inpatient dataset), Scottish death register and Paediatric Intensive Care Audit Network (PICANet) database. Transitions were defined as: unstable stage - an emergency inpatient admission that lasted 48 hours or more; unstable phase - any emergency PICU admission; dying - last 28 days before death. CYP were stable if alive and not in one of the other stages. Transitions between stages of condition were determined for each cohort member and most severe stage determined on a 1, 3, 6 and 12-month basis. Numbers in each stage were determined overall and by age group. A monthly mean of the daily numbers in each stage of condition was also determined.

Results

Over 2200 CYP were unstable, deteriorating or dying in each year. In 2010/11, most severe stage of condition was stable for 10678 (83%); unstable for 1816 (14%); deteriorating for 253 (2%) and dying for 183 (1%). Over shorter periods the stable fraction increased: using a one month sampling period (April 2010) the most severe stages of condition were: 1990 (97%) of CYP stable, 367 (3%) unstable, 33 (0.3%) deteriorating and 17 (0.1%) dying. However, the yearly figures for instability were

lower (e.g. 1816 were unstable as most severe stage in 2010/11) than the sum of monthly totals (summing monthly figures for 2010/2011, 4367 were unstable). On an average day (mean for April 2010) 12222 (99%) were stable; 135 (1%) unstable; 14 (0.1%) deteriorating and 5 (<0.1%) dying. The effects of changing sampling period were greatest for under 1 year olds.

Conclusions

The differences dependent on the sampling period show the degree of variability in the group of patients experiencing instability, with different individuals having periods of instability at different points in the year, but also some individuals having multiple episodes of instability. In informing healthcare provision and planning, it is important to understand these differences in numbers in each category across different time periods.

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