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Comparing identification of children and young people with a life limiting condition from cause of death with use of an ICD-10 coding framework applied to routine clinical data

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Objective

To compare methods of estimating prevalence of life limiting conditions (LLC) among children and young people (CYP) using (i) cause of death recorded on death certificates and (ii) diagnostic codes in routinely collected inpatient and birth records.

Approach

CYP with a LLC were identified from NHS inpatient and birth records in Scotland from 1 April 2003 to 30 March 2014 using a LLC ICD-10 coding framework. The cohort was restricted to individuals who died in the study period. For each cohort member, the LLC coding framework was used to determine whether a diagnosis identified as a LLC was recorded as the underlying cause of death. For those without LLC as an underlying cause of death, the underlying cause was checked to determine whether it was related to LLC - either itself indicative of LLC when recorded on a death certificate or related to one or more of the LLCs identified in the individual's inpatient and birth records. Finally, for those with underlying cause of death neither a LLC nor related to a LLC, the contributing causes of death were checked against the coding framework for LLC; where found, the individual was marked as having a LLC as a contributing cause of death. These analyses were undertaken for the whole cohort, per year, by age groups and by diagnostic categories.

Results

20436 CYP with a LLC were identified between 1 April 2009 and 31 March 2014, of which 2249 had died and had a death register record. Of these, 1291 (57%) had a LLC as underlying cause of death; 319 (14%) had an LLC-related underlying cause of death and 268 (12%) had LLC only among contributing causes of death. 371 (16%) had no indication of LLC in their death

records. Recording of a LLC as underlying cause of death was lower (41%) amongst under 1 year olds and also varied widely by diagnostic group.

Conclusions

Around one in six of CYP identified using the coding framework as having a LLC (and almost one in five of under 1s) would not have been so identified using all causes of death in death records. More than a quarter (28%) would be missed if only underlying cause of death was used. This, combined with longer survival times, means use of death records has the potential to greatly underestimate prevalence of LLC in children and young people.

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