Children with Life-Limiting Conditions: Establishing Accurate Prevalence Figures

Abstract:

Sir

Children's palliative care is a new and evolving specialty. In order to ascertain accurate data on the number of children requiring services, a number of countries, including Ireland, have undertaken children's palliative care needs assessments. Regardless of the country of origin, the findings of these needs assessments are very similar. Irish child (0–17 years) population figures indicate that there are approximately 1.2 million children in Ireland. Hampered by ambiguity surrounding definitions and the lack of a national database, currently there are no definitive data on the number of these children living with a life-limiting condition.

In the absence of a national database on children with life-limiting conditions, data from a needs assessment published in 2005 continues to be utilised. In this needs assessment calculations for the number of children living with a life-limiting condition in Ireland were extrapolated from UK data which at the time, reported a prevalence rate of 12:10,000 child population. This was utilised although known to be an underestimate. Applying this ratio to Irish census data the researchers estimated 1,369 children were living with a life-limiting condition in Ireland. Cultural factors that may impact on the accuracy of these estimates for example, the legislation governing termination of pregnancy in Ireland were not considered despite the likelihood of impacting on the number of children born and surviving with complex care needs and conditions that may result in premature death. A more recently published Irish report examined prevalence figures further and after considering international evidence a higher median prevalence figure of 14.5:10,000 per child population was used to plan for the development of respite services for children with life-limiting conditions.

Researchers in England, in order to gather more robust data on prevalence utilised the English Hospital Episode Statistics Dataset and International Classification of Disease Data. Analysis suggests that the true prevalence of children living with a life-limiting condition is at least 32:10,000 child population and may be as high as 44:10,000. Historically Irish prevalence rates are based on the UK data therefore, application of the 32:10,000 figure to recent child population data suggests that there are 3840 children in Ireland living with a life-limiting condition. It is clear from both national and international data that the original figure of 1369 children living with a life-limiting condition is an underestimate. Findings from England indicate an approximate three-fold increase on original estimates. This has significant implications for service provision and workforce planning. The national children's palliative care policy is widely viewed as the blueprint for the future development of children's palliative care in Ireland, in light of these findings this document needs to be reviewed and the implications of this significantly increased prevalence of children with life-limiting conditions needs to be considered by service planners, care providers and policy makers alike.

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References


Comments: