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Cystic Fibrosis Research News

Title:

A guide to interpreting estimated median age of survival in cystic fibrosis patient registry reports

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What was your research question?

Our aim was to provide a clear explanation of the meaning of the 'median survival age' reported in cystic fibrosis (CF) annual registry reports and to make recommendations to registries about how to report information about survival. We also wanted to explain how the figure is calculated and what assumptions it makes.

Why is this important?

Survival statistics, estimated using data collected by national CF patient registries, are used to inform the CF community and monitor groups of people with CF. Annual registry reports typically give the median age of survival. However, different registries have presented and explained the figure of median survival age in different ways. This had led to confusion in the CF community. It is important to provide clear and accurate information to the CF community and to explain the limitations of the calculated median age of survival.

What did you do?

We outlined the statistical methods that are used to estimate median age of survival using registry data and provided wording that can be used across registry reports. We also explained that the median age of survival refers to survival from birth and is not relevant for people who are living with CF at an older age. The use of 'conditional' survival statistics was recommended to provide information for people who have already reached an older age, e.g.

age 30. To illustrate our recommendations, we gave examples based on analysis of the UK CF Registry.

What did you find?

Median survival age is an estimate of the age beyond which we expect half of a population of individuals born today with CF to live. The interpretation of the median survival age of 47 in the UK is that in a population of babies born today with CF, half would be expected to live beyond age 47. The median survival age conditional on living to age 30 is 55, meaning that 50% of 30 year olds with CF today are expected to live beyond age 55. Together with these estimates it is also important to provide information about their uncertainty.

What does this mean and reasons for caution?

We recommend consistent and accurate reporting of median survival age in registry reports, which acknowledges the assumptions and uncertainties of the calculations. The way in which the median survival age is estimated assumes that mortality rates in the future will be similar to those today. Although it represents the best information available to us currently, it does not take into account recent and future improvements in care and treatment that will impact survival. The median survival age refers to a population and not an individual; it does not take into account individual features that impact survival.

What's next?

This work has already resulted in changes to the reporting of median survival age in registry reports. This work focused on population-level survival. In forthcoming work we are providing personalised information about survival based on patient characteristics such as lung function.

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