Cystic Fibrosis Research News

Title:

Direct healthcare costs in the first 2 years of life: a comparison of screened and clinically diagnosed children with Cystic Fibrosis- the Irish Comparative Outcomes Study of CF (ICOS)

Lay Title:

Comparing the money spent on healthcare up to age 2 years in children with CF who are screen detected and those who are diagnosed later due to sickness.

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What was your research question?

We know that newborn screening improves outcomes in CF. We now wanted to see how introducing newborn screening (NBS) in Ireland in 2011 had reduced the healthcare costs to the Government, compared with the costs for children diagnosed through sickness, in the time before the introduction of screening.

Why is this important?

Looking at the cost benefits allows national and international governments to have a better understanding of the benefits of the CF NBS programme. Our study data were from a national

population NBS programme, and the costs were collected and analysed more or less at the same time. Other studies were not able to do this and include cystic fibrosis registry data only (which may not capture all children with CF) or look back at data collected in the past.

What did you do?

Our study of CF has been running in Ireland since 2013. Most parents consented to be part of our national study (93%) with 232 patients with CF included in this study. Using information from the Cystic Fibrosis Registry of Ireland (CFRI), medical records (for those children who were not registered with CFRI) and a questionnaire to parents (for information on the child in the time before the CF diagnosis). We included hospital admissions, emergency department visits, outpatient appointments, antibiotics and routine medications. We were able to use the standard costs used to count healthcare costs in Ireland to work out our costs.

What did you find?

We found that children born before screening was introduced and diagnosed with clinical illness had costs which were over two and half times the costs of the screen-detected child.
The additional costs were related mostly to the increased hospital stays, a mixture of stays before the diagnosis of CF was made and more hospital admissions after the diagnosis also. There were higher costs for IV antibiotics. Those who were screen-detected had higher costs for oral antibiotics and for day case and outpatient visits, due to the fact that these will start routinely as soon as the child is diagnosed.

What does this mean and reasons for caution?

This shows another benefit of NBS for CF. However, there are reasons for caution.
In Ireland the Government pays for all healthcare for children with CF. This does not happen in every country. Healthcare costs in different countries will vary – so what matters is costs over 2.5 times in clinically diagnosed rather than the actual money.
We used information collected before CFTR modulators were introduced. Children in Ireland can now start CFTR modulators at age 2. So, if we continued the cost comparison to include older children, we would add CFTR modulators and so the cost difference might change.

What's next?

We have continued our study, and we will be examining older children and will look at the difference in costs which will include the expensive CFTR modulators, which will give the up-to-date comparisons.

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