Journal of Cystic Fibrosis
The Official Journal of the European Cystic Fibrosis Society

CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

Cystic Fibrosis Research News

Citation:

Stephenson AL, Sykes J, Stanojevic S, Quon BS, Marshall BC, Petren K, Ostrenga J, Fink AK, Elbert A, Goss CH. Survival Comparison of Patients with Cystic Fibrosis in Canada and the United States: A Population-Based Cohort Study. Annals of Internal Medicine. 2016 Jul;13(7):1173-9. PMID: 27078236.

What was your research question? (50 words maximum)

In 2011, the median age of survival for cystic fibrosis (CF) patients in the U.S. was 36.8 years, whereas it was 48.5 years in the Canada. We wanted to use a standardized approach to confirm these results. We also wanted to explore the differences between the United States and Canada.

Why is this important? (100 words maximum)

Comparing data on CF patients in different countries registries has led to important discoveries in CF disease progression. However, direct comparisons between countries are not always accurate due to differences in data collection. The use of a standardized approach to data processing and survival calculations will help improve confidence in international comparisons. Through standardized comparisons, we can also identify which factors, such as access to healthcare or prescribing practices, contribute to the observed differences.

What did you do? (100 words maximum)

We collected data from 42 Canadian and 110 US CF care centers for the years 1990 to 2013 using the Canadian Cystic Fibrosis Registry (CCFR) and U.S. Cystic Fibrosis Foundation Patient Registry (CFFPR), respectively. We compared the data definitions and how data are collected in each country and standardized the measurements of each variable between countries. We then used

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statistical analysis to compare demographic and clinical variables, with adjustments being made for patient and clinical characteristics.

What did you find? (100 words maximum)

Our study confirms that there is a significant survival gap between Canada and the United States for people living with CF. For the period of 2009 to 2010, a 10-year survival advantage was identified for patients living in Canada. The risk of death was consistently lower in Canada after accounting for several demographic and clinical factors, even in patients with more severe disease. Several of our findings support the hypothesis that differences in transplantation and healthcare coverage may be contributing to the observed survival gap. There was a higher percentage of Canadian patients with healthcare coverage and a higher percentage of patients who received a lung transplant, and these factors may contribute to the higher survival rate of Canadian patients.

What does this mean and reasons for caution? (100 words maximum)

The systematic approach used to compare data from these two countries demonstrates that national disease registries can be compared successfully. It also can help us understand factors associated with differences in survival. A reason for caution with these findings is that there could be possible bias due to missing data or patients being lost to follow-up in the registries.

What's next? (50 words maximum)

We cannot draw conclusions about the reasons for survival differences between the US and Canada from these analyses, but they are still important. The observed differences have raised the question of whether a disparity exists in access to proper healthcare or the delivery of healthcare from providers.

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Further investigation will be needed to understand more about these observed differences.