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Cystic Fibrosis Research News

Title:

Controversies with Kalydeco: Newspaper Coverage in Canada and the Unites States of the Cystic Fibrosis "Wonder Drug"

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What was your research question?

How have newspaper articles in Canada and the U.S. portrayed the development of or patient access to Kalydeco?

Why is this important?

Kalydeco is the first drug to address the underlying causes of Cystic Fibrosis (CF) for roughly 2% of CF patients who have a rare mutation of the gene and has been called a "wonder drug" because it is has been so effective. However, it also has a cost per patient of $300, 000/year, which raises a lot of questions about why it is so expensive and who will pay for it. Many people get their health information from the news media, and the media coverage of Kalydeco can influence what people know about the drug, how they perceive the related issues, and can also influence how policies and other funding decisions are made.

What did you do?

We analyzed 290 newspaper articles that were published in newspapers in Canada and the U.S. between October 2011 and January 2015. For each article, we made note of the perspective of the article (Was it a medical story, financial story, patient story, or a policy story?), and the description of Kalydeco and any discussions of the drug's development or patients' access to the drug. We also recorded whether each article supported or opposed government subsidization of patient access to Kalydeco.

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What did you find?

We found that the majority of Canadian newspaper articles focused on stories about CF patients who want government funding for Kalydeco. Most of these stories were supportive of government funding,but rarely questioned how the government would pay for the drug. The newspaper articles in the U.S. focused more on the success of Kalydeco as a medical breakthrough and for its boost to the pharmaceutical industry.

What does this mean and reasons for caution?

The differences in Canadian and U.S. news coverage may reflect the differences in their healthcare systems. Canada, and other countries with publicly funded healthcare systems, will need to make tough decisions about drug coverage in the face of shrinking budgets. This is increasingly important as new drugs enter the market, for example, Orkambi. The combination of Kalydeco and Orkambi is designed to treat CF patients with the most common mutation of the gene, which is roughly 75% of CF patients. News coverage that focuses on patient stories that do not include information about scientific evidence and budget limitations may influence how these decisions are made.

What's next?

Funding decisions about Kalydeco continue to make the news, and as new drugs, like Orkambi, enter the market, it will be interesting to see if and how news coverage begins to grapple with policy issues and patient access to expensive medications.

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