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Title:

END-OF-LIFE PRACTICE PATTERNS AT U.S. ADULT CYSTIC FIBROSIS CARE CENTERS: A NATIONAL RETROSPECTIVE CHART REVIEW

Authors:

Elaine Chen (a), Karen Homa (b), Jessica Goggin (c), Kathryn A Sabadosa (d), Sarah Hempstead (e), Bruce C Marshall (e), Albert Faro (e), Elisabeth P Dellon (f).

Affiliations:

a Rush University Medical Center, Chicago, IL, United States

b Independent Consultant, Orford, NH, United States

c University of California, San Diego, CA, United States

d The Dartmouth Institute for Health Policy & Clinical Practice, Geisel School of Medicine at Dartmouth, Lebanon, NH, United States

e Cystic Fibrosis Foundation, Bethesda, MD, United States

f University of North Carolina School of Medicine, Chapel Hill, NC, United States

What was your research question?

We studied end-of-life care in adults with cystic fibrosis (CF) throughout the United States. We wanted to better understand the issues faced by people with CF as they get older and as their lung disease gets worse, and to identify any differences between the centers.

Why is this important?

CF care is improving, people with CF are living longer, and lung transplants are becoming more common. As people with CF get older and lung transplant outcomes improve, end-of-life care for CF is becoming more complicated. Our hope is to improve care for people with CF at the end of life. In order to make improvements and recommendations, we first need to understand current practices in end-of-life care.

What did you do?

We invited all 113 US adult CF care programs to review medical records of the last 5 patients who received care in each program and died between 2011 and 2013. This information included age, cause and location of death, whether they were waiting for a lung transplant, whether hospice or palliative care were utilized, and whether certain medical treatments were received close to death. We also reviewed how well symptoms like pain and shortness

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cfresearchnews@gmail.com



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of breath were treated, and whether people who died had designated someone to make health care decisions if they were unable to do so themselves.

What did you find?

72 programs shared information on 242 adults with CF who died during that time. Most of the people with CF died in a hospital, often in an intensive care unit. Many people were waiting for a lung transplant. Hospice and palliative care, which are considered markers for good end-of-life care, were not often used by people with CF. Advance care planning, which is a communication process intended to align medical treatments with an individual's goals and wishes, is important for people with chronic illness but wasn't often done in people with CF in this study.

What does this mean and reasons for caution?

There is a lot of variation in the type of end-of-life care that people with CF receive, and it is hard to predict when people with CF are getting nearer to death. Therefore, it is important to help people with CF talk about these difficult issues with their families and care teams when they feel well. We relied on reports from the medical records of people who died from CF, however, these records may be missing some information. Additionally, we are not certain whether the practices of programs opting to participate in this study represent those of all US adult programs.

What's next?

In order to improve end-of-life care for people with CF, we are working to develop palliative care recommendations and educational tools to help health care teams take better care of people with CF throughout their lives, including at end of life.

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