



Cystic Fibrosis Research News

Title:

A PROSPECTIVE ANALYSIS OF UNPLANNED PATIENT-INITIATED CONTACTS IN AN ADULT CYSTIC FIBROSIS CENTRE

Authors:

Espérie Burnet¹, Dominique Hubert¹, Juliette Champreux¹, Isabelle Honore¹, Reem Kanaan¹, Rosewilita Panzo¹, Pierre-Régis Burgel^{1,2}

Affiliations:

¹ Adult Cystic Fibrosis Centre, Cochin Hospital, Assistance Publique-Hôpitaux de Paris, Paris, France

² Université Paris Descartes, Sorbonne Paris Cité, Paris, France

What was your research question?

We decided to explore why and how patients contacted the CF centre outside of scheduled contacts, how much time was spent answering their requests or concerns, and whether patients with lower lung function were more likely to contact us more frequently.

Why is this important?

In people with cystic fibrosis (CF), the prevention and early recognition of complications plays a crucial role in maintaining health and quality of life. While most aspects of patient care can be planned in advance during clinic visits, a reliable and efficient channel of communication between the patient/family and the health care team must be in place to ensure continuity of care in between scheduled events.

What did you do?

We conducted a two-stage study, first from 1 January to 30 April, 2015, which involved the participation of four physicians and three nurses, then continued to 31 December, 2015, with the same three nurses and one physician. All participating nurses and physicians documented each patient contact and recorded the reason(s) and method used. In the second part of the study, the medical characteristics of the patients were also collected and we analysed whether patients who had more severe lung function contacted us more frequently.

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cfresearchnews@gmail.com



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What did you find?

Most patients initiated at least one unscheduled contact to the CF centre over the year. Contacts were made primarily via email with physicians and via telephone with nurses. The average time spent responding to patient-initiated contacts was 8 hours/week, or one hour and 37 minutes per day. Contact time was longer for nurses than for physicians. Less than 20% of contacts were related to symptoms management, with other reasons ranging from holiday planning to daily CF health management and administrative issues. Patients with an FEV1 lower than 30% contacted us five times more frequently than those with an FEV1 greater 60%.

What does this mean and reasons for caution?

The diversity of reasons for contacting the CF centre clearly shows that CF is a complex disease and that the CF centre should provide comprehensive expertise in primary care to CF patients. The recognition of the high workload associated with answering phone or email contacts should trigger thinking about appropriate ways for patients to access information and advice from the CF centre. Improving the efficiency of patient communication with the CF centre could also include a telephone triage system that would direct patient contacts to the appropriate provider or staff.

What's next?

Whatever the means of communication between patients and caregivers, it is paramount to have sufficient staff to answer patient requests and/or concerns and for staff members to have the expertise necessary to identify urgent situations.

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