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Original Article

A prospective analysis of unplanned patient-initiated contacts in an adult cystic fibrosis centre☆

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Abstract

Background: Timely response should be provided when patients contact the cystic fibrosis (CF) centre in between scheduled visits. Little data exist on unplanned patient-initiated contacts in CF adults.
Methods: A two-stage prospective study was undertaken from 1 January to 31 December 2015 at Cochin Hospital, Paris (France). The first stage included all adults (≥18 years) who initiated unplanned contacts to the CF centre over four months. Four physicians and three nurses systematically recorded unplanned patient-initiated contacts. The data was analysed to determine why and how patients contacted the CF centre and time spent responding to their request(s). The second stage (one physician, three nurses) lasted twelve months and explored whether high contact frequency was associated with disease severity, using multivariate logistic regression.
Results: In the first stage, 259 of 410 patients (63%) initiated at least one unplanned contact, corresponding to 1067 contacts over 4 months. Patients favoured email with physicians (61% of contacts) and telephone with nurses (87% of contacts). Total time spent by the 7 caregivers on providing responses was 8 h/work week. Reasons for contacting the CF centre varied greatly, but <20% of contacts were directly related to symptom management. In the second stage, 180 of 212 patients (85%) initiated 1876 contacts over 12 months. Factors associated with ≥5 contacts/year were female sex, FEV_1 ≤ 30% predicted, ≥5 physician visits/year, and ≥ 1 hospital admission/year.
Conclusions: Answering unplanned patient-initiated contacts represented a significant workload for CF caregivers. Increased disease severity was associated with high contact frequency.

Keywords: Patient-initiated contact; Contact frequency; Ambulatory care; Outpatient; Continuity of care; Telephone triage

1. Introduction

In people with cystic fibrosis (CF), the prevention and early recognition of complications plays a crucial role in improving patient outcomes [3]. Yet, as more patients move into adulthood, their professional, school and family lives often take precedence over the management of their illness. While most aspects of patient care can be planned in advance during clinic visits and hospitalisations, 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 [4,5].

Abbreviations: BMI, Body Mass Index; CF, Cystic Fibrosis; FEV_1% pred., Forced Expiratory Volume in 1 s, percent predicted value; IV, Intravenous.

☆ **Data previously presented at:**

- ECFS 2016, Basle, Switzerland (Poster) [1]
- ECFS 2017, Seville, Spain (Poster) [2]
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The European consensus on standards of care in patients with CF emphasizes the need for patients to have access to the CF centre "for telephone advice or for emergencies or other consultations" [5]. A prerequisite for this to be effective is that an appropriate and timely response is provided when patients contact the CF centre. Adequate staff and infrastructure capacity are therefore essential for answering patient concerns and ensuring their safety.

Little is known, however, about the nature of patient-initiated contacts, their frequency or the associated workload. Understanding what motivates patients to contact the CF centre could help improve the organisation of outpatient care and thus provide a more adapted response to patient needs. At Cochin CF centre, a large adult CF centre in Paris (France), noticing that an important share of our activity was dedicated to responding to unplanned patient-initiated contacts, we sought to explore why and how patients contacted the CF centre, how much time was spent answering their requests or concerns, and whether greater clinical severity was associated with greater contact frequency.

2. Methods

We conducted a two-stage prospective longitudinal study, exploring the nature of unplanned patient-initiated contacts – defined as a telephone call, an email, a text message or a visit to the CF centre – that was not planned during a previous consultation or hospitalisation and that was initiated by the patient or a family member.

The first stage sought to describe why and how patients contacted the CF centre, which members of the health care team (physicians or nurses) were contacted and how much time was spent answering their requests or concerns. It took place over four months, between 1 January and 30 April 2015. Four CF physicians (of four in the CF centre) and three CF nurses (of four in the CF centre) participated. All patients who were followed for CF at Cochin hospital during the four-month study period (n = 410, all aged ≥18 years) and who initiated an unplanned contact to a participating physician or nurse were included.

All participating physicians and nurses carried a data collection sheet and systematically recorded every unplanned patient-initiated contact, including the reason(s), method used, and response time. All nurses and one physician had a direct telephone line that could take calls from outside the hospital. The other three physicians could be reached through a call transfer from the front desk staff or from any line within the hospital. All physicians and nurses had access to email on personal computers and/or smartphones. For logistical reasons and to focus on the clinical aspects of patient care, we did not include contacts to other members of the team (e.g., social worker, psychologist, dietitian…). Similarly, because our goal was to focus on time spent by CF caregivers, we did not include visits or calls to the Emergency Department of our hospital. Night and weekend communications by Email were captured in our analysis, but phone calls received outside working hours (8 am to 6 pm, Monday to Friday) were not counted due to the absence of a voice messaging system at our centre. To capture the total time spent on responding to patient requests, all contacts were recorded, including duplicate calls and/or emails to several members of the health care team. The time spent on the response included the time spent on the intervention (i.e. writing a prescription, filling a form or liaising with other health care providers). For nurses, it also included discussing the matter with a physician, a pharmacist or a home care nurse.

Contact data was collated at regular intervals by the primary researcher. The reasons why patients contacted the CF centre, entered as free text in the collection sheets, were grouped into five categories (clinical symptoms, daily management, long-term issues, administrative tasks and questions related to intravenous antibiotic courses). For contacts that contained more than one request/concern, all issues raised by the patient were recorded. Percentages were calculated for each category, using the total number of requests/concerns, rather than the total number of contacts, as the denominator. Method used for contact and time spent on response were analysed on a per contact basis.

The second stage aimed to explore whether greater patient clinical severity was associated with greater contact frequency. It lasted from 1 January to 31 December 2015. Inclusion criteria were limited to CF patients followed by the physician with a direct telephone line and 100% CF activity (the other three physicians dedicated 20% to 50% of their activity to CF). All CF patients followed by this physician were included (n = 212 in December 2015), whether or not they initiated an unplanned contact. As in the first stage, contact data was collected systematically by the participating physician and the same three nurses. Clinical data and patient characteristics were collected retrospectively from patient files by the primary researcher.

The association between patient disease severity and contact frequency was evaluated in univariate and multivariable analysis using logistic regression. Disease severity was defined based on forced expiratory volume in 1 s (FEV_1, best value in 2015) and grouped in three categories: >60% predicted, 31–60% predicted and ≤30% predicted. Other variables included in the analysis were age, body mass index (BMI), and the number of physician visits, hospital admissions and intravenous (IV, including both inpatient and outpatient) antibiotic courses in 2015.

Since only seven of the 212 patients (3.3%) were followed for <10 months in 2015, contact frequency was defined as the total number of unplanned patient-initiated contacts over the year rather than contacts per patient per month. High contact frequency was defined as five or more contacts/year, based on a median for the cohort of 4 contacts/patient.

2.1. Statistical analysis

Categorical data were described as n (%) and continuous data as median (interquartile range (IQR) and/or min–max). Univariate logistic regression analysis was conducted to evaluate the association between each variable and high contact frequency. Chi-squared tests were used to test for statistical significance and a p-value < 0.05 was considered to provide sufficient evidence to support an association. A multivariate logistic regression model was built using the variables that were found to be associated with high contact frequency and disease severity in univariate analysis, providing they did not lie on the

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