Quality improvement in your CF centre: taking care of care

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Abstract

Cystic fibrosis (CF) centres can assess the quality of the care they deliver by benchmarking their practices and outcomes against those of other CF centres. This is most easily done using summaries of electronic patient records, such as are generated by patient registries. All centres should assess their compliance with standards of care, as determined by consensus documents and evidence-based medicine, and continually seek out and implement ways to improve their clinical outcomes. This may imply changes to routine centre practice as well as to treatment strategies.

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1. Introduction

From the youngest age, cystic fibrosis (CF) patients depend on their care givers to mount a team effort that offers them the longest life expectancy and best possible quality of life. The topic of this presentation is how to identify and implement best practices in CF care.

2. Benchmarking

Benchmarking is a term used to describe the evaluation of one’s own performance in comparison to someone else’s, according to specified standards, in order to improve one’s performance. It implies the search for those best practices that are associated with superior outcomes as well as discovering new methods, ideas and tools to improve effectiveness, and paying attention to the subtleties of care, in other words “stealing good ideas shamelessly”. Many parameters can be benchmarked, including body mass index, percentage of patients on standard of care, lung function determinants, CT score, quality of life and percentage of patients chronically infected with Pseudomonas aeruginosa among many others.

Selected indicators can be used to evaluate performance within a single centre on a year-to-year basis as well as for centre-to-centre comparisons [1]. Especially for the latter, correction for various confounders such as genotype, age distribution and socio-economic class is needed.

3. Requirements for an effective CF centre

The CF team should be coordinated by a CF centre director. The core CF team consists of a lung physician, gastroenterologist, specialized nurse(s), physiotherapist(s), dietitian, social worker, psychologist, clinical pharmacist and clinical microbiologist. Other specialists with expertise in CF should be close at hand such as a geneticist, abdominal / thoracic surgeon, and gynaecologist. Ideally a centre should consist of a paediatric and an adult unit working closely together to facilitate seamless transition and to support the critical mass of the CF team. A European consensus on standards of care has been published [2].
In order to maintain sufficient expertise, each centre should care for a minimum of 50 CF children or adults [2]. There are many reasons why centralised care in clinics of sufficient size is important. Firstly, CF care requires a complete CF team whose members must invest a great deal of time in continuing education and must innovate care to the highest possible level. Scientific developments are occurring at an ever faster pace; patients are well informed about these developments and rightly require that the care they receive meet international standards. Secondly, the infrastructure required to provide the best of care to CF patients is becoming more and more costly. This infrastructure must include in- and out-patient facilities that permit appropriate infection control, access to lung function and CF microbiology laboratories and imaging facilities, as well as on-line access to all diagnostic data and to its own electronic database of CF patient records. Furthermore, it must be able to provide education to CF patients and their families and should participate in properly conducted, preferably international, clinical research. Financial commitment from hospital management is mandatory to maintain the infrastructure and the complete multidisciplinary team of essential CF specialists at the appropriate level. Thirdly, it is well recognized that a large enough number of patients is important in generating and maintaining adequate expertise in the complicated disease that CF is.

Despite the consensus that the minimal size for a centre is 50 CF patients, it is surprising that in many countries patients are still being cared for in smaller centres [1]. Hence, further centralization of CF care should be considered an important opportunity to enhance care in a cost-efficient way.

4. Facilities at the Sophia Children’s Hospital

Our clinic at the Erasmus Medical Centre – Sophia Children’s Hospital, where 150 children with CF are treated, is dedicated to optimizing care for CF patients and provides access to the facilities listed in Table 1. An electronic patient record is essential for easy and complete access to key data. It permits review of the patient’s history within a few minutes before the patient enters the examination room. The physician can efficiently and completely evaluate all relevant complexities of the patient’s clinical care, including longitudinal trends from graphic display of important indicators such as Body Mass Index (BMI) or lung function parameters such as the forced expiratory volume in one second (FEV₁). Hence, the risk of overlooking relevant information is reduced and unnecessary questions to the patient can be avoided. The graphic display of key indicators can be shown to the patient to explain certain treatment decisions or to encourage adherence to therapy. Our electronic record is also set up to provide patient education materials automatically as required. Furthermore, it structures care because it forces the clinician to use standardized forms for clinical follow-up visits and to schedule, for example, the routine annual check-up using an electronic form where mandatory and optional items are listed separately. Port-CF, the web-based data collection vehicle of the US Cystic Fibrosis Foundation Patient Register (CFFPR, http://www.cff.org/CCNP/Register/) that will be used in the near future by many European CF centres, offers similar advantages. Like other registries, it also allows compilation of anonymised data from many centres into comprehensive reports that aid in the clinical management of CF.

5. Optimising routine centre practices

Analysis of multi-centre data compiled into patient registries provides many clues about the most successful current practices. For example, a recent presentation from the CFFPR reported that teenagers were more likely than other CF patients to lose >5% of their lung function per year [3]. A pertinent previous analysis, performed by the Epidemiologic Study of Cystic Fibrosis (ESCF), found that the CF centres with the best outcomes in terms of FEV₁ performed more frequent spirometry and sputum cultures and prescribed more frequent and longer courses of intravenous antibiotics than other centres, particularly in teenagers with only mild to moderate lung function impairment [4]. Thus, it seems particularly important for optimum health to detect and treat acute lung infections in adolescents. Furthermore, Boyle pointed out that, although very few young patients are seen only once or twice per year, the proportion rises to over 30% in patients over 18 years of age, suggesting that older patients may need to be seen more frequently, starting in the teenage years [3].

6. Optimising treatment strategies

Medical treatments should be evidence-based and, while there have been few controlled clinical trials in the past, their number is increasing even if the median sample size is still too small [5]. The power of trials to answer important clinical questions can be improved only by establishing clinical trial networks [6]. Despite this recent progress in the science of CF care, individual CF centres are still inconsistent in their implementation of evidence-based therapies. For example, a consortium of six CF centres in the United States compared their therapeutic strategies and found that the percentage...

of eligible patients who received evidence-based treatment ranged from 20% to 75% for dornase alfa and from 40 to 90% for inhaled tobramycin [7]. The reason given for most of the patients not receiving these treatments was that they were perceived as well (Figs. 1 and 2). This is a striking finding since the intention of these therapies is primarily to prevent deterioration in order to maintain lung health [8]. After the centres in the consortium had agreed on how the therapies should be prescribed and had instituted a quality improvement program, the use of both treatments became less variable and exceeded the national average (Figs. 3 and 4).

7. Summary

The key to improving quality of care in any CF centre is the care team’s eagerness to improve care. Visits to other centres offer an opportunity to learn and to “steal good ideas shamelessly”. CF centres should manage a minimum of 50 patients in order to hone their expertise. Electronic patient records are a powerful tool to optimize patient care. The attitude of CF teams should be to refuse any loss in lung function, especially during puberty, by the consistent implementation of evidence-based medicine. Adjusting care to the highest standards and measuring its impact on outcomes should be a key goal of every CF team.

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