Benchmarking improves quality in cystic fibrosis care: a pilot project involving 12 centres

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Abstract

Objective. Health care quality monitoring has been introduced in cystic fibrosis (CF) by a few groups and national registries. Based upon this, continuous quality improvement can be achieved by applying the benchmarking method which is focused on learning from best practice.

Setting. A group of 12 CF centres in Germany, treating a total of 1200 patients of all ages, enrolled in a nationwide pilot benchmarking project from 2004 to 2007.

Intervention. Key nutritional and respiratory parameters were used as quality indicators. Numerical benchmarks were set and used for ranking. Applying the plan-do-check-act cycle, quality improvement interventions were introduced, such as harmonization of definitions and references, improvement of measurement standards, data quality, completion of missing data, enforcement of early aggressive antibiotic treatment and individual adaptation of dietary counseling.

Results. Ranking alone was not sufficient for identification of the best performing centres unless it was accompanied by longitudinal follow-up. Improvement was possible in the 3 years’ period as shown by benchmarking for single centres that introduced new interventions in nutritional and antibiotic treatment most consequently.

Conclusion. CF provides a model of the link between processes of health care delivery and health outcomes of patients. Quality improvement is a continuous goal in CF care with realistic potential as exemplified by our data. Accountability was introduced and transparency was improved by our pilot benchmarking project. Using the benchmarking procedure, our long-term project will reinforce standards, programmes, and individual attitudes and principles to ensure continuous quality improvement in CF health care.

Keywords: benchmarking, centre care, cystic fibrosis, epidemiology, quality improvement

Introduction

Cystic fibrosis (CF) remains an incurable disease that can be treated effectively by taking a multidisciplinary approach. However, the care delivered is not always optimal, and substantial quality improvement in CF care can still be achieved by studying the results of various centres and by learning from the best performing centres [1]. Nutritional strategy [2], aggressive antibiotic strategy [3, 4] and specialized centre care [5] have been shown to improve the health of CF patients.

Accepted indicators of quality, such as body mass index (BMI) for nutrition and forced expiratory volume in one second (FEV1) for respiratory function, have been adapted by a small number of centres as benchmarks for CF care [6–10]. Benchmarking of institutions, based on health outcomes, enables identification of best practices of care. After the identification of best practice, it is possible for participants to learn from the best centres.

The German Cystic Fibrosis Quality Assurance (CFQA) project [11, 12] has enabled German CF centres to progress from registry to quality management. Our aim was to show that quality improvement in CF care is indeed possible. Twelve German CF centres have participated in this educational project since 2004. A solid benchmarking group could thus be formed. The purpose of this paper is to provide an example of our approach.
Methods

Organization

The German CFQA project [11] served as the backbone of the benchmarking project which began on 1 July 2004, and ended on 31 December 2007. This project was supported by the German Ministry of Health. The Centre for Quality and Management in Health Care (ZQ Hannover) was responsible for the project management, coordination and methodical development. Each German CF institution had been contacted prior to the project, and 12 centres participated voluntarily. The size (number of patients) and composition (age of patients) of the centres were heterogeneous (Fig. 1; single centres, A–L).

Data

Electronic documentation of each patient’s visits was based entirely on the CFQA software system CFAS 2.6 [11]. The upper acceptable limit for missing values relating to quality indicators was 5%, and participants were required to complete the data before the evaluation was carried out. The project collected variables included age, sex, respiratory function, weight, height, presence/absence of Pseudomonas aeruginosa and Burkholderia cepacia and history of medical complications [11]. The benchmarking evaluation was based exclusively on outpatient visits [13], the frequency of which was 4.1 ± 2.1 (median 4.0) per year. No significant differences in the frequency of outpatient visits were observed during the 3-year period. For the purpose of the evaluation, written informed consent was obtained from the parents and/or patients.

Quality indicators

The project used the following indicators of quality: the presence of Pseudomonas aeruginosa, weight for height (WH), BMI, FEV1, maximal expiratory forced flow 25% (MEF25) and the presence of massive complications (pneumothorax, severe haemoptysis, global pulmonary insufficiency, distal intestinal obstruction syndrome).

Weight and height data were used to calculate the predicted percentage of WH in children and adolescents as well as BMI in adults. Patients were defined as malnourished if WH was <90% of the predicted references for sex and height in children or if the BMI was <19 kg m⁻² in adults [14–16]. Respiratory function was considered abnormal if FEV1 was <80% and/or MEF25 was <60% of the predicted reference value [17, 18]. These figures have been used as minimum acceptable measurements for benchmarking.

Each CF centre was assessed separately on the basis of the above quality indicators and calculation of the proportion of patients for whom the indicator objectives were achieved. Using performance on these indicators, it was possible to identify benchmarks (= “highest rates”) indicating best practices. During two annual conferences, the best clinical practices were identified based on the benchmarks. In addition, measures for quality improvement in several CF centres were established: improvement of data quality, establishing of checklists for fulfilling diagnostic standards, optimization of measurements, e.g. weight, respiratory function and microbiological assessment, improvement of patient recall and empowerment, better communication of results inside the group, improvement of infection control, individualization of dietary counselling and better compliance with guidelines.
Best practice was marked by ranking and follow-up. The four centres reaching best marks were asked to define their specific strategy (more aggressive, earlier and more consistent antibiotic therapy and infection control, more individualized intensified dietary counselling and follow-up). These points of best practice were used by the other centres to feed a learning process and quality improvement procedure.

Consensus was achieved on different measures to improve treatment, above all by treating *Pseudomonas aeruginosa* infection earlier and more aggressively and by tailoring dietary counselling towards individual needs (intensifying frequency of visits, nutritional survey and introducing supplementary feeding and percutaneous endoscopic gastrostomy whenever necessary). Discussions during these regular one-day meetings were facilitated by appointing two external moderators (ZQ Hannover), who attended all meetings without exemption and who have been assessing all data from all centres.

**Quality improvement process**

The process of quality improvement based on the benchmarking approach entailed open internal discussions,
generating an atmosphere of trust and a mutual understanding with regard to the exchange of experience and information collected. Centre leaders and physicians as well as documentation officers participated in the internal discussions. Discussions have not been made public, third parties have been excluded and confidentiality has been monitored. Benchmarking was utilized to improve quality by means of the plan-do-check-act (PDCA) cycle. Three such cycles were scheduled for the 3-year span from 2004 to 2007. The emphasis during the first stage was on developing the operational procedure; while the focus in the second phase was on validation and, in the third, attention was paid to opening the benchmarking approach to all the centres within the CFQA project. Three institutional rankings and two evaluations of a CF quality of life questionnaire [19] targeting the years 2005 and 2006 were scheduled.

Since quality improvement has to be an on-going process, the results presented in this paper illustrate the benchmarking approach and call for further action and correction. Modifications were made during the first 2 years of the benchmarking project to improve accountability of differences in quality, e.g. the improvement of measurements (weight, respiratory function), enforcement of correct use of definitions and standards and completion of missing data. This in itself represented a part of the quality improvements achieved. Thereafter, rankings of the participating centres were done, based on the key nutritional parameters (weight for height and BMI), and the main respiratory parameter (FEV1). The ranking of the participating centres was based on weight for height, BMI and FEV1, especially in the second and third PDCA cycle and these indicators were used to evaluate the impact of the clinical interventions made by the centres.

Figure 3 CF benchmarking in Germany. Ranking of centres according to: percentages of patients free of Pseudomonas aeruginosa. (a) Patients under 18 years of age. (b) Patients 18 years and older. All individual centres are indicated by capital letters.
Statistics

For statistical analysis, data were transferred to the Statistical Package for Social Sciences (Version 14.0, SPSS, Inc., Chicago, IL, USA). Cross-sectional and longitudinal analyses were carried out. Differences in means, in variances of means and in frequencies between groups were analysed using common parametric and non-parametric statistical methods. Mixed linear models served for longitudinal analysis. P-values < 0.05 were considered statistically significant.

Results

Ranking of centres

All centres were ranked based on nutritional parameters (WH and BMI) and the respiratory parameter (FEV1). The ranking data from the third PDCA cycle are given in Fig. 2a–d. These ranking data were also used to test the efficacy of quality improvement interventions. We observed considerable differences between the centres with regard to FEV1 in children and adolescents. Among adult patients, these variations were even more pronounced (Fig. 2d). Centres C and A showed relatively good results for WH in the younger patients, while centres C and B showed good results for FEV1 in the younger age group. The variation in ranks reflected in part the heterogeneity of centres. Nevertheless, ranking was instrumental in classifying best practice and induced vivid group discussions as a basis for quality improvement.

Figure 3 indicates the rate of success achieved for the benchmark ‘free of Pseudomonas aeruginosa’, which was defined as the absence of Pseudomonas aeruginosa for a complete year, substantiated by a minimum of four investigations at the respective centres for children and adolescents (Fig. 3a) and adult patients (Fig. 3b). Again, centre C showed a good position, closer to the upper end. Differences between the two age groups (Fig. 3a vs. b) were anticipated. A statistically highly significant correlation was found between the presence of Pseudomonas aeruginosa and reduced FEV1 (mean FEV1 98.9 vs. 87.3% in children and adolescents, 72.2 vs. 56.4% in adults, P < 0.001).

Efficacy (3-year follow-up)

Performance on infection control increased most in institution C compared with the other centres while centre A increased the rate of systematic nutritional therapy more than the other centres. To evaluate the efficacy of these measures and the effect of benchmarking, longitudinal analyses were performed (Fig 4a–d). The changes in four individual centres (A, B, C and D) can be identified during the 3-year period, whereas the

![Figure 4 CF benchmarking in Germany. Three-year follow-up (years 1, 2, 3).](https://academic.oup.com/intqhc/article-abstract/23/3/349/1793718)
remaining centres did not show significant changes (E–L, n = 8) and are depicted together (in grey). Figure 4a and b clearly show that nutritional data were relatively favourable in A and C. Additional improvements were noticeable in both centres during the 3-year period, and were attributable to improved nutritional counselling. A similar tendency was observed only in the case of younger patients at D (= specific measures only for this group) (Fig. 4a and b). Interestingly, although B started at the lower end, it achieved some improvement in both age groups. It is possible that the combination of these skills and attitudes were as important as having sufficient leadership, a competent CF team and the determination to change. These skills and attitudes were as important as their ability to make these changes. Key characteristics of centres which centres shared information with each other, but not with external, third parties. Ranking of the main nutritional parameters, WH and BMI, and of the key respiratory parameter, FEV₁, has been applied to the patients’ groups. Patients’ age was not a sole and eminent factor determining positions in ranking reached by different institutions. One main success of the project was the evidence that the individual ranking position of an institution alone was not the main objective of the learning process. Identification, analysis and discussion of the practices followed in centres with the best results (e.g. centres with the highest ranking) provided operational guidance for other centres. Discussion indicated that a dynamic discussion was required to identify the attitudes and practices which constituted best practice. Discussions stimulated by the ranking procedure led to many changes at the introductory stage of the study, such as enforcement of the use of correct definitions and standards and improvement of measurements (above all, weight and respiratory function). The completion of missing data led to better comparability and ensured follow-up. Data quality was thus improved throughout the process, and a new software system was developed accordingly (MUKO.dok) [25]. The use of two external moderators has proved to be very valuable for the benchmarking procedure. Many additional tools and skills have been developed over the course of the project (improved use of diagnostic standards, checklists, guidelines, improved patient recall and empowerment, creation of data transparency, frank discussions and leadership towards improvement). After conclusion of the first phase of CF benchmarking in Germany, a communication process has been started to spread data and experiences from the pilot project to the entire CFQA project. As a consequence, 23 accredited institutions, taking care of >2200 patients of all ages, are presently included in our continuing project. In addition, information is being shared with patients and their institutions (Mukoviszidose e.V.) to spread decisive knowledge about best processes of CF care to the entire CF community.

**Discussion**

Benchmarking is a potent tool for accelerating quality improvement in CF care. Learning from the best, pursuing excellence, appropriate leadership and the courage to introduce the necessary changes in an atmosphere of mutual trust are important aspects. Measurements of performance and data transparency are possible today in CF care, when based on well-established CF registries, such as the CFQA in Germany which has existed since 1995 [11]. Centre care is revisited during the benchmarking project. Quality improvement can be led to new horizons by creating continuous quality awareness in the participating, dedicated CF centres. This includes single, more specific projects involving individual centres committed to the improvement of nutritional and respiratory outcomes by appropriate means in their CF patients [20]. It also includes more general educational approaches involving groups of highly motivated CF centres which use benchmarking as a common educational approach (all teach, all learn), as has been reported from New England [21] and in this paper. This was an essential step forward in comparison to the previous work which mainly focused on reporting the descriptive stage of care patterns and outcome parameters at different centres [3, 4, 22–24].

Within the pilot project of the German CFQA system, it was possible to create an atmosphere of trust among the 12 centres in the benchmarking group. Each centre was ready to participate in an intensive 3-year programme in
as formal changes like intensive group work with external moderators, harmonization of definitions, aggressive infection control and systematic nutritional therapy. The skills, attitudes and formal changes have been communicated to the other centres to facilitate improvement wherever necessary.

Different settings have been reported, particularly from the USA, in which the potential of quality improvement can be accelerated by benchmarking in CF care [8, 20, 21]. Many of the positive developments seen in these settings have been attributed to superior systems, attitudes, practices and projects [20], and not to one-off, extraordinary procedures. Therefore, extension of the benchmarking concept, to include more patients and potentially all centres in Germany has now been started; it involves the work of several regional groups, practising the PDCA cycle, refining benchmarks, checking defined changes towards better CF care and participating in a world-wide discussion about best strategies. Specifically, in our benchmarking work, we will focus on the following items: evaluation of detailed antibiotic treatment in chronic Pseudomonas aeruginosa infection [30], management of CF diabetes mellitus, and management of allergic broncho-pulmonary aspergillosis. In addition, inclusion of an entry level for patients, by means of a CF questionnaire (quality of life), has already begun. It is hoped that more insight will be thereby gained into the complex relationship between objective/medical and subjective/personal aspects of quality improvement in CF care. Future strategies and patient-centred CF healthcare systems are very likely [31] to employ the tool of benchmarking.

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