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Editorial, by Jeannette E. Dankert-Roelse

Change, yes, we can!

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With this slogan Barack Obama was elected president of the USA on 4 November 2008, the day the 3rd Quality Round Table was held in Frankfurt, and possibly this slogan inspires us too. Because that is what we strive for: a change for the better in CF care in Europe. A global change for the worse happened at the same time: it is evident now that the financial crisis will touch everyone. However, one of the least costly ways to bring change to almost everyone may be by Internet and the way ECORN-CF is organized, so let's try to use it.

In this issue of the ECORN-newsletter, we report about how the answers that were given in the course of 2008 were scored by members of ECORN-CF and the results of these assessments. During the meeting, we brainstormed how we can provide positive feedback in such a way that everyone can learn from it. Due to the sometimes divergent opinions about the quality of the answers, this clearly is not an easy task and the way how to do it is not easily solved.

The second task of ECORN-CF is to find gaps in our knowledge not covered by current CF guidelines. From the questions asked it became clear that many patients have practical concerns about traveling with CF, but doctors and CF care team members mostly don't have answers, because practically all guidelines are limited to medical issues. More and more patients with CF learn to live with their condition but don't want the way they like to live be constrained by it. A consensus about traveling is on its way and will be published for patients as well as CF-teams hopefully before the end of 2009. You can read more about this project in this newsletter.

In the article about the CF-awareness day you can read how necessary change in CF care throughout Europe is and how important it is to use all means, including ECORN-CF to achieve this. Put a note in your agendas – the next CF-awareness day will be on 11 November 2009 – and read what is expected from you on this day.

Report from the 3rd Quality Round Table Frankfurt, 4 November 2008

Participants: Sophie BUCHBERGER, Frankfurt, Germany; Wojciech CICHY, Poland; Ioana CIUCA, Romania; Daniela D'ALQUEN, Würzburg, Germany; Edvardas DANILA, Lithuania; Jeannette DANKERT-ROELSE, Netherlands; Kris DE BOECK, Belgium; Karleen DE RIJCKE, Belgium; Gerd DÖRING, Tübingen, Germany; Tereza FISCHEROVÁ, Czech Republic; Wolfgang GLEIBER, Frankfurt, Germany (partly); Tim HIRCHE, Frankfurt, Germany (partly); Hans KOLLBERG, Sweden; Annette PFALZ, Frankfurt, Germany; Gilles RAULT, France; Burkhard TÜMMLER, Hannover, Germany; Thomas WAGNER, Frankfurt, Germany

Quality control within ECORN-CF

An important theme of this meeting was the Quality control within ECORN-CF. A major aim of ECORN-CF is learning from each other and bringing knowledge and know-how about CF at a

higher level in the participating EU countries. Moreover, the questions and answers are put in the Archive after translation into the English language and become available for everyone visiting the ECORN website. Therefore, the answers should be indisputable in content and form.

A large part of this meeting was spent on the issue whether the present quality of the answers to the questions is sufficient. Besides, it is expected, and in fact one of the main aims of the ECORN project, that in the course of time the answers will improve.

The coordinators of the quality control work package organized a study to assess the current quality of the answers and whether the answers improve over time.

From all questions received so far, 55 questions from 5 countries were selected, then mixed and blinded; local details from which the originating country could be deduced were deleted as much as possible.

Five ECORN participants from 4 different countries assessed the answers (K. De Boeck, Belgium, H. Hebestreit, Germany, V. Vávrová, Czech Republic, J. Bradley, United Kingdom and B. Dembski, Germany)

The process of the assessment of the answers was performed as follows:

I. Content quality

The answers were scored on three aspects: Were the answers

1. correct/according to guidelines?
2. complete and suitable?
3. clear and open?

Possible scores: poor 0 points; satisfactory 1 point; good 2 points.

The first item – is the answer correct and according to guidelines – is the most important aspect; therefore this item had the greatest weight in the total score and a maximum score of 6 points could be given. For the 2 other aspects the maximal scores was 2 points, which makes a maximal total score of 10 points.

II. Formal quality

The answers were scored again on three aspects: were the answers

1. understandable for the questioner (either patient or layperson)
2. personal and friendly
3. of a suitable extent in relation to the question, and sufficiently detailed?

For each item a maximum score of 2 points could be given (poor 0, satisfactory 1, and good 2 points), with a total maximal score of 6.

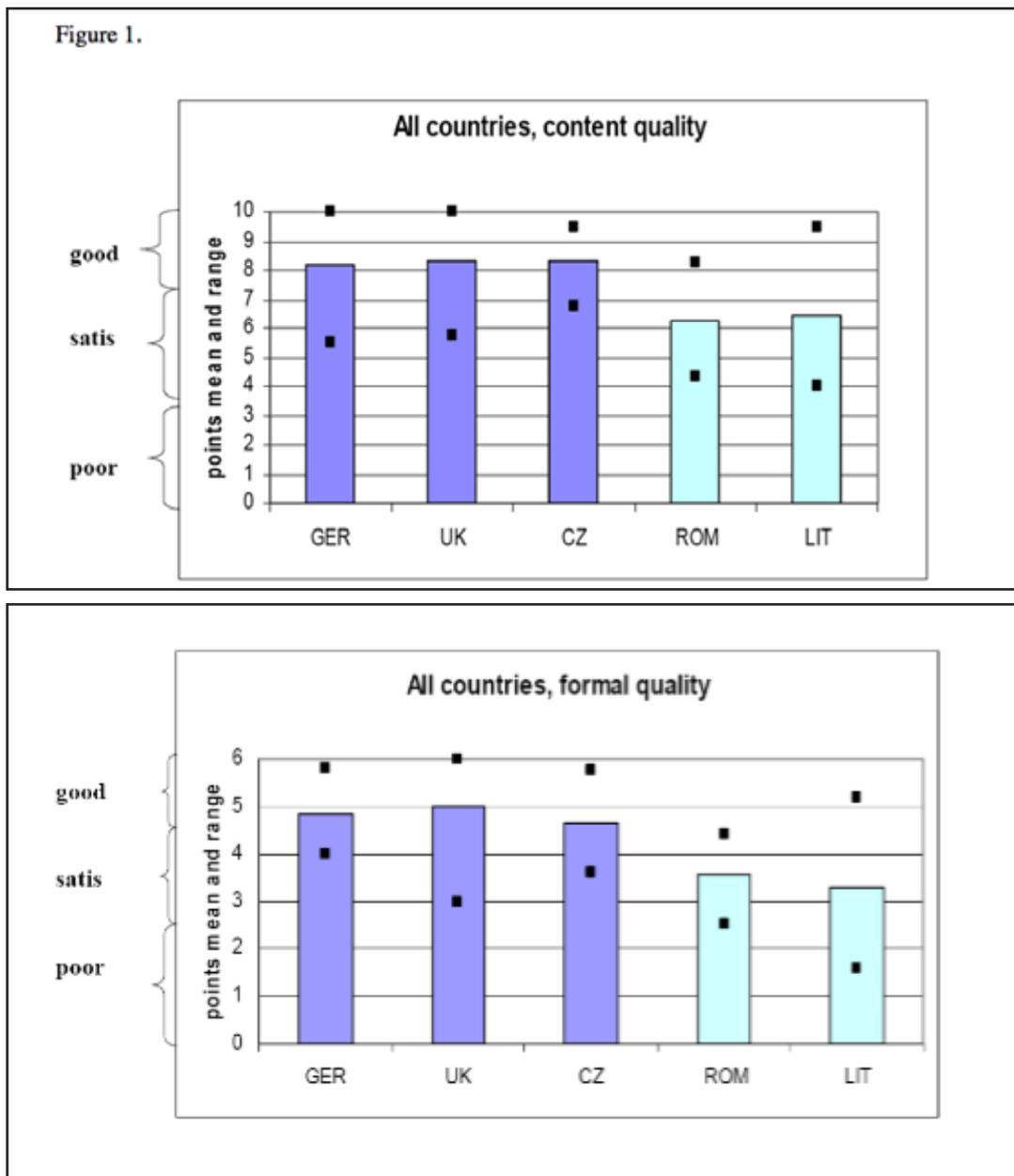
Most of the questions came from the German website (20), 10 from the Czech Republic, 5 from Romania, 10 from Lithuania, and 10 from the UK.

The German, Czech and English websites were launched on October 1, 2007; until 1 September 2008, the German website received 149 questions, about 3 per week; the Czech website received 64 questions, 1.5 per week; and the English website received 12 questions, 1 per month. The Romanian website came online on 19 December 2007 and received 10 questions, 1 per month; and the Lithuanian website came online on 31 January 2008 and received a total of 10 questions usable for scoring, 1 per month.

No assessments could yet be made for the Dutch and the Polish websites, which started in March and April 2008, respectively.

The total scores in the 5 countries are shown in Figure 1 for content quality and in Figure 2 for the formal quality.

Agreement between the scorers varied strongly. For some questions complete agreement was found but for others the scores varied between poor and good. There was the tendency of a greater difference among the formal scores than the content scores



Conclusions

The German, English and Czech websites have an overall “good” mean of their content and formal quality. The Romanian and Lithuanian websites were scored with a mean of “satisfactory” which means that there is room for improvement.

Due to the small numbers and the relatively short time period, no improvement in time was found.

During the discussion following the presentation of the results, the participants of the meeting wondered how the questioners would have assessed the answers and whether it would be possible to get more insight in the opinion of the users of the websites. It was not possible to change the website with a pop-up asking the questioner if he or she is satisfied with the answer. Therefore an extra question (“How satisfied were you with the answer to your question?”) was added to the questionnaire that is sent to the registered questioners.

Another issue was how we can best detect the weak points in the answers, because this might help to avoid these in the future. One of the suggested ways was to do a fine-scoring of all the questions on all the scored items. When a strong disagreement is found for the content quality, there is a need to discuss the answers before publication on the website.

However, the feedback process in general for the expert answers, in other words the publishing in the Archive, should be sped up.

After this presentation a few interesting questions were discussed, which were presented by Kris de Boeck ("The Vest and Physiotherapy"), Gerd Döring ("MRSA") and Burkhard Tümmler ("Two children with CF in a common building").

Consensus Meeting Frankfurt, 4 and 5 November 2008

While the first part of the meeting was dedicated to the first aim of ECORN-CF, namely to provide transfer of knowledge and expertise throughout Europe to guarantee the same level of expert advice in all EU countries, the second part of the meeting focused on another important aim of ECORN, namely to find deficits in guidelines as well as a way to fill in these deficits.

Furthermore the program will help to extract data on deficits in existing guidelines or lack of evidence based guidelines and to find an European consensus for care of CF-patients where it is necessary.

Many questions that are posed on the website are related to traveling, which indicates that CF patients are often in such good health that nowadays traveling around the world like their peers do is a possibility for many young CF-patients. Therefore, "Traveling with CF" was chosen as the subject of the consensus meeting.

The following topics were discussed during the meeting:

Preparation before traveling

- Contraindications for traveling (instable disease, pneumothorax)
- Risk factors related with destinations
- Physical examination, flight tests
- Infrastructure abroad (patient-organizations, CF-hospitals, emergencies)
- CF health/travel insurance
- Specific documents (customs, forms, medical letter)

Traveling with CF-On site

- Prevention of salt depletion
- Sports and physical activities
- Groups meetings/segregation
- Specific needs/recommendations following lung transplantation, immunosuppression

General agreement about the consensus

The consensus will be divided into two parts: the first one will deal with advice on how best to prepare for a trip, including issues such as choice of destination, travel insurance, medical equipment and medication, and so forth; the second one will focus on issues that need to be considered at the destination itself. Rather than taking an exclusively medical approach, the main goal of this consensus is to provide patient-oriented advice that exceeds pure medical aspects in offering very practical tips and suggestions for all aspects involved in planning and making a trip. This will be useful for the patients themselves, but it will also be of help for doctors and other CF care team members. These often get a lot of these practical questions from patients but may not always be sure how to answer them. Ideally, there will also be a brochure resulting from this eventually.

The next steps that are to be made are:

- to produce a uniform document from the presentations given on the various issues.
- to ask patients to review this document.
- then the document will be sent out to external experts for a critical appraisal
- to circulate the revised document among the ECORN-CF members for their feedback.

By the time of the 4th Quality Round Table and Consensus meeting in October 2009, a close-to-final version is planned to be discussed again and approved for submission to the ECFS

Karleen de Rijcke reported the following about the initiative of the annual CF awareness day, which has been taking place every November since 2006. It is an initiative which again shows the need of projects like ECORN-CF, namely to provide transfer of knowledge and expertise throughout Europe to guarantee the same level of expert advice in all EU countries.

Cystic Fibrosis (CF) is the most frequent life threatening genetic disease in Europe. In some countries the median age at death of people with Cystic Fibrosis is more than 35 years, in other countries the majority of children die before their 5th birthday! Guidelines for best standards of care were developed to ensure appropriate treatment in Europe. In countries where these guidelines are followed and appropriate care is provided and where patients have full access to medication and treatments, life expectancy is now more than 40 years. Most children have few symptoms and serious problems can be delayed until adulthood. In regions where the disease is not yet well known and access to appropriate care is poor, the life expectancy and quality of life are still very low. With the 3rd European CF Awareness day we continued our fight for equal access to appropriate care for all children and people living with this disease in Europe!

Some CF patients get to 40 years old... others 4, depending on where they live in Europe

All over Europe a lot of patients are never diagnosed and too many patients die too young. But there are major regional differences. A CFE survey on CF data in Europe from 2006 shows that about 50% of the persons with CF are 18 years or older in countries where CF care is well-developed; in other regions it is less than 20%. In some countries people with CF can expect to get 40 years old or older, in others the average age at death is less than 4 years! In countries where CF knowledge is low, the majority of patients are not diagnosed and if diagnosed, patients have poor access to specialized health professionals, essential medication and medical materials needed to survive.

Access to appropriate CF care is inefficient throughout Europe

Although the living conditions of CF patients are especially hard in most of the new EU countries and the countries not (yet) belonging to the EU, the deficiencies in CF care and access to appropriate care are not limited to this region. Problems to get access to care occur in countries with weaker and stronger economies and poor access to optimal care is limited by other than financial barriers.

Some examples from the EU:

- In Belgium, 1 of 7 patients ask the national patient association for financial help to cover the treatment costs.
- In Germany, only 50% of the treatment costs are paid by the German health care insurances. The other 50% have to be covered from other sources like donations, research projects etc. Therefore, the German CF association with a budget of € 500 000 in 2006 as well as the Christiane Herzog Foundation set up financial programs to support CF clinics.
- In Greece, the number of hospitals, single-bed rooms as well as medical staff who have received special training for CF is small or non-existent.
- In Ireland, the median age at death in 2000 was only 17 years compared to 30 years in neighboring regions (major progress was made after the independent Pollack Study as well as a national campaign for an adequate number of multidisciplinary CF clinics and segregation measures).
- In Latvia, only 6 % of patients are diagnosed; there is no specialized CF center and only one doctor interested in CF

Deficiencies in CF care in Europe due to more than financial barriers!

The above examples and the survey on CF data clearly show that access to appropriate care is not only limited due to financial means. CF care in Europe should and could be improved without necessarily having to invest a lot of money.

European Standards of care offer best guarantee to optimal care

For more than 40 years now, the CF community – patients, their families, doctors, other caregivers and scientists – has been struggling against Cystic Fibrosis. Today scientific and medical knowledge about the biological causes of CF and the way to treat this disastrous disease is far advanced. In 2005 a European Consensus of Standards of CF Care was published, in which 36 experts from 15 European countries, the USA, Israel and Russia were involved. In countries offering well-developed CF care in hospitals which follow these guidelines, about 50% of the CF patients are 18 years and older, and the average life expectancy is 40 years and more. The lives of CF patients depend on correct treatment according to these standards.

Strategies to improve care with relatively little investment

- In the treatment of CF, *preventing complications* is a priority. This can prolong and save lives, but also save extra health costs. It is more expensive to treat severely ill patients in the hospital than to pay for the essential medication that can be taken at home to prevent symptoms. If a patient is regularly checked by specialists trained in the treatment of CF and receives the correct antibiotics, as soon as an infection occurs, expensive and uncomfortable hospitalizations can be avoided.
- An adequate number of *CF clinics observing the European standard of CF* mentioned above should be established in each European country. In some countries no specialized clinics are available (or not within reach of a majority of the patients); in other countries CF care is spread over too many clinics where the staff is insufficiently specialized and experienced. This costs society a lot to and also endangers the CF patients' lives.
- *Prevention of infection* in the clinics by proper hygienic and segregation measures is essential to improving the quality of life and the survival chances.
- *Offer the essential treatments for free.* We realize that some countries do not have the means to reimburse all necessary medication and care. Therefore it is important that authorities discuss with patient representatives and specialists which are the most needed treatments. In several countries, basic treatments are not available while other, more expensive but less essential medication is reimbursed.
- *Offer training and education for CF patients and their families and health care professionals* on CF and home care (e.g. use of medication, physiotherapy to clear patients' lungs from the sticky mucus and high calorie diet to prevent malnutrition).

All over Europe patients and caregivers fight together for better access to care

On this 3rd European CF Awareness Day, associations all over Europe organized events to improve the knowledge about CF in their region and to raise awareness for the general public, the authorities, health professionals, patients and families.

The main event was the Conference V4-CF "Better? Why not? Together we could do more," organized by the Polish CF Foundation MATIO, Slovak CF Association, Klub nemocn_ch cystickou fibrózou and the Hungarian Cystic Fibrosis Association from 20 to 22 November 2008 in Krakow, Poland (www.v4-cf.eu). This conference created an ideal platform to exchange experiences about CF care in the region and made it possible to work on a common strategy to move towards equal access to appropriate care in all countries.

Forthcoming events



32nd European Cystic Fibrosis Conference

10 - 13 June 2009 - Brest, France



4th Quality Round Table and Consensus Meeting: 6 - 7 October 2009,
Prague, Czech Republic

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