European Cystic Fibrosis Society

Journal of Cystic Fibrosis
The Official Journal of the European Cystic Fibrosis Society

Cystic Fibrosis Research News

Title:

"Il faut continuer à poser des questions" patient reported outcome measures in cystic fibrosis: An anthropological perspective

Authors:

Rosa Coucke[a], Audrey Chansard[b], Véronique Bontemps[c], Dominique Grenet[d], Dominique Hubert[e], Clémence Martin[e], Elise Lammertyn[b], Emmanuelle Bardin[b], Veerle Bulteel[f], Frédérique Chedevergne[a], Muriel Le Bourgeois[a], Pierre-Régis Burgel[e], Isabelle Honore[e], Hilde de Keyser[b], Maya Kirszenbaum[a], Paola de Carli[g], Isabelle Sermet-Gaudelus[a], and Kate Hayes[h,f]
And on behalf of the European Cystic Fibrosis Society-Clinical Trials Network Patient Advisory Group:
Jutta Bend, Claire Bresnihan, Anne Calvert, Anna Fonts, Andreas Hager, Maxime Hautrive, Trudy Havermans, Diana Hofmann.

Affiliations:

[a] Service de Pneumologie et Allergologie Pédiatriques, Centre de Ressourcés et de Compétence de la Mucoviscidose, Hôpital Necker Enfants Malades 149 rue de Sévres, INSERM U1151, Institut Necker Enfants Malades, Université Paris Sorbonne, Paris 75743, France.
[b] CF Europe, Joseph Borlélaan 12, 1160 Brussels, Belgium.
[c] Institut de Recherche Interdisciplinaire sur les Enjeux Sociaux, Campus Condorcet, Bâtiment Recherche Sud, 5 cours de Humanitiés, 93322 Aubervillers cedex.
[d] Hôpital Foch, 40 rue Worth, 92150 Suresnes, France
[e] Hôpital Cochin, Assistance Publique Hôpitaux de Paris and Université de Paris, Institut Cochin, Inserm U1016, 27 rue du Faubourg Saint-Jacques, 75014 Paris
[f] European Cystic Fibrosis Society, Karup, Denmark
[g] Association Vaincre la Mucoviscidose, 181 rue de Tolbiac, 75013 Paris
[h] Northern Ireland Clinical Research Facility, The Wellcome-Wolfson Centre for Experimental Medicine, Queen's University Belfast, 97 Lisburn Road, Belfast BT9 7BL.

What was your research question?

We looked at patient reported outcome measures: questionnaires that assess quality of life and symptoms reported by people with CF (pwCF), to see what are commonly used. We then asked a group of French pwCF and parents to review the commonly used "cystic fibrosis questionnaire" (the CFQ).

Cystic Fibrosis Research News

Why is this important?

Many questionnaires to help pwCF report how they are feeling and managing their CF are out-of-date, created over 20 years ago. Many pwCF are living longer, healthier lives and we need a new modern questionnaire, to better understand the things that matter most to them and their families. We wanted to see what was important to pwCF and their families. Guidance from patients will help us build a new better questionnaire to look at the areas of their lives that are most important to them.

What did you do?

We did two surveys, one to look at the questionnaires that pwCF use most often during a routine visit to their CF clinic and one to look at the questionnaires used in clinical trials in CF centres across Europe. We also asked over 100 pwCF and their families what they thought about a commonly used French questionnaire called the CFQ. They told us what should be improved and how to make a useful questionnaire that highlights the most important impacts of their CF and its treatments on their lives.

What did you find?

We found that many of the tools commonly used are out-of-date. People with CF and their families told us to remove questions that focus on the negative impacts of CF and to ask more questions about the different kinds of treatments and their impact on day-to-day life. More questions are needed on things like relationships, family, stress, mood and future plans. These are all very important to pwCF and they felt that these should be included in any new questionnaire.

What does this mean and reasons for caution?

This study had pwCF as the experts looking at a common French CF questionnaire to see what areas could be changed to make a tool that is more up-to-date and useful for pwCF, their families and healthcare providers. Interviewing pwCF and their families is a useful way to find out about areas that are important from the patients' point of view. Future research could include pwCF from other countries and use computer programmes to analyse their answers to find the most important ideas for a future questionnaire.

What's next?

This study showed the need for new patient reported outcomes in CF and highlighted the importance of looking at CF research from the patients' point of view. It also showed us the importance of working in partnership, with patients, families, the European CF Society Clinical Trial Network and CF Europe.

Original manuscript citation in PubMed
https://pubmed.ncbi.nlm.nih.gov/33648900/