Background

✓ Caregivers are more and more aware of the need for education in patients with CF, but education is time consuming.

✓ The French working group for CF patient education (GETHEM) has elaborated a questionnaire “words to say” designed to allow patients to quickly express their expectations in 8 different fields.

✓ The aim of our study was to evaluate the first version of this questionnaire among our patients with CF.
Patients and Methods

✓ This prospective study was conducted from October to December 2012 at our adult CF centre during outpatient visits.

✓ Consecutive patients were asked to complete the self-administered questionnaire “words to say”. They had to check words corresponding to the themes they wanted to discuss with their doctor.

✓ It was planned to collect 100 completed questionnaires.
# Questionnaire “words to say”

## Socio-professional life
- Job, schedules
- Absenteeism
- Social rights
- Recreation
- Holidays
- Money
- Transportation

## Organisation of the day
- Shopping
- Resting time
- Planning activities/care

## Family life
- Household
- Hygiene
- Family
- Relations

## Sexuality
- Postures
- Breathlessness
- Libido
- Sexually transmissible disease
- Vaginal dryness
- Body image

## Psychological feeling
- Mood
- Depression
- Overwhelming disease

## Discomfort associated with CF
- Incontinence
- Gas
- Smelling stools
- Sputum
- Cough
- Pain
- Fatigue
- Mycosis

## Treatment
- Regularity
- Discontinuation
- Decreased frequency
- Efficacy

## Procreation
- Medical assisted procreation
- Child desire
Results – Characteristics of the patients

✓ 18 patients did not completed the questionnaire and 100 patients did

✓ Characteristics of the 100 patients who responded

- 48 males and 52 females
- mean age: 34 ± 9 years (18-69)
- mean FEV1 : 52.4 ± 19.7 % pred.
- mean BMI : 21.1 ± 3.3 kg/m²
- activity : 10 students, 58 in the labour force, 34 inactive
- family life : 60 living in couples, 30 with children
Results – Topics of interest

Patients who ticked at least one word in the topic

<table>
<thead>
<tr>
<th>Topic</th>
<th>Percentage of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>discomfort associated with CF</td>
<td>86</td>
</tr>
<tr>
<td>socio-professional life</td>
<td>64</td>
</tr>
<tr>
<td>treatment</td>
<td>52</td>
</tr>
<tr>
<td>psychological feeling</td>
<td>51</td>
</tr>
<tr>
<td>family life</td>
<td>39</td>
</tr>
<tr>
<td>organisation of the day</td>
<td>33</td>
</tr>
<tr>
<td>procreation</td>
<td>29</td>
</tr>
<tr>
<td>sexuality</td>
<td>19</td>
</tr>
</tbody>
</table>
Results – Frequently ticked words

Words ticked by > 25% of the patients

<table>
<thead>
<tr>
<th>Word</th>
<th>Percentage of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>fatigue</td>
<td>59</td>
</tr>
<tr>
<td>pain</td>
<td>40</td>
</tr>
<tr>
<td>treatment efficacy</td>
<td>38</td>
</tr>
<tr>
<td>cough</td>
<td>36</td>
</tr>
<tr>
<td>mood</td>
<td>32</td>
</tr>
<tr>
<td>sputum</td>
<td>31</td>
</tr>
<tr>
<td>social rights</td>
<td>31</td>
</tr>
<tr>
<td>job</td>
<td>27</td>
</tr>
</tbody>
</table>
Looking at the questionnaire with the patient

- The questionnaire helped the patient to express his expectations
- Responses helped the physician to prepare the visit with the patient
- In case only one or two words were ticked, the points could be discussed with the patient during the visit
- Otherwise, we proposed to plan an education session later on
- According to the patient’s requests, we proposed him to meet the social worker (questions about social rights or job), the psychologist, another caregiver or the CF physician (questions about symptoms or treatment)
New version of the questionnaire

1. Social and family life
   added: couple, children, talking of disease, having a child

2. Socio-professional life
   added: Studies and studying abroad

3. Sexual life
   added: contraception, positions, pain

4. Psychological feeling
   added: self esteem, anxiety, motivation, efficacy feeling

5. Symptoms due to the disease
   added: quality of sleep

6. Organisation of everyday life

7. Recreation becomes a new topic

8. Treatment
   added: new treatment, transplantation, assisted medical procreation

9. Projects becomes a new topic
Conclusion

✓ This self-administered questionnaire “words to say” allowed to improve communication between adult CF patients and their caregivers.

✓ It was used as a basis for further education.

✓ Patients’ main concern were:
  • discomfort associated with CF (primarily fatigue and pain)
  • treatment efficacy
  • social rights
  • procedures to keep or find a job.

✓ The responses and the caregivers’ comments helped to build a new version of this self administered questionnaire “words to say”.