

Improving communication between adults with cystic fibrosis and their CF physician

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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

Treatment

- Regularity
- Discontinuation
- Decreased frequency
- Efficacy

Discomfort associated with CF

- Incontinence
- Gas
- Smelling stools
- Sputum
- Cough
- Pain
- Fatigue
- Mycosis

Procreation

- Medial assisted procreation
- Child desire

Psychological feeling

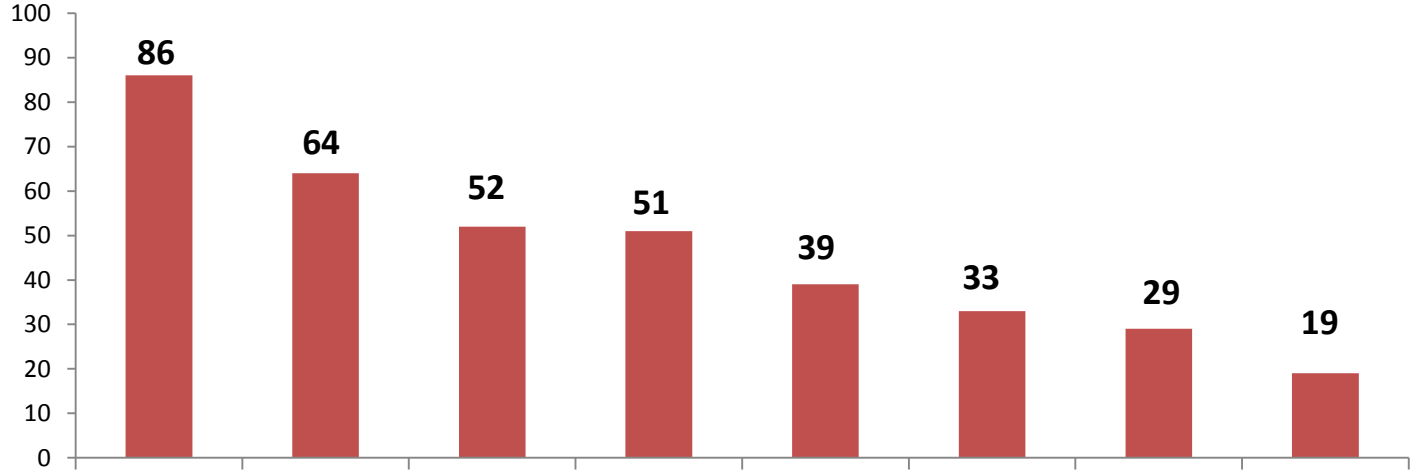
- Mood
- Depression
- Overwhelming disease

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

percentage of patients



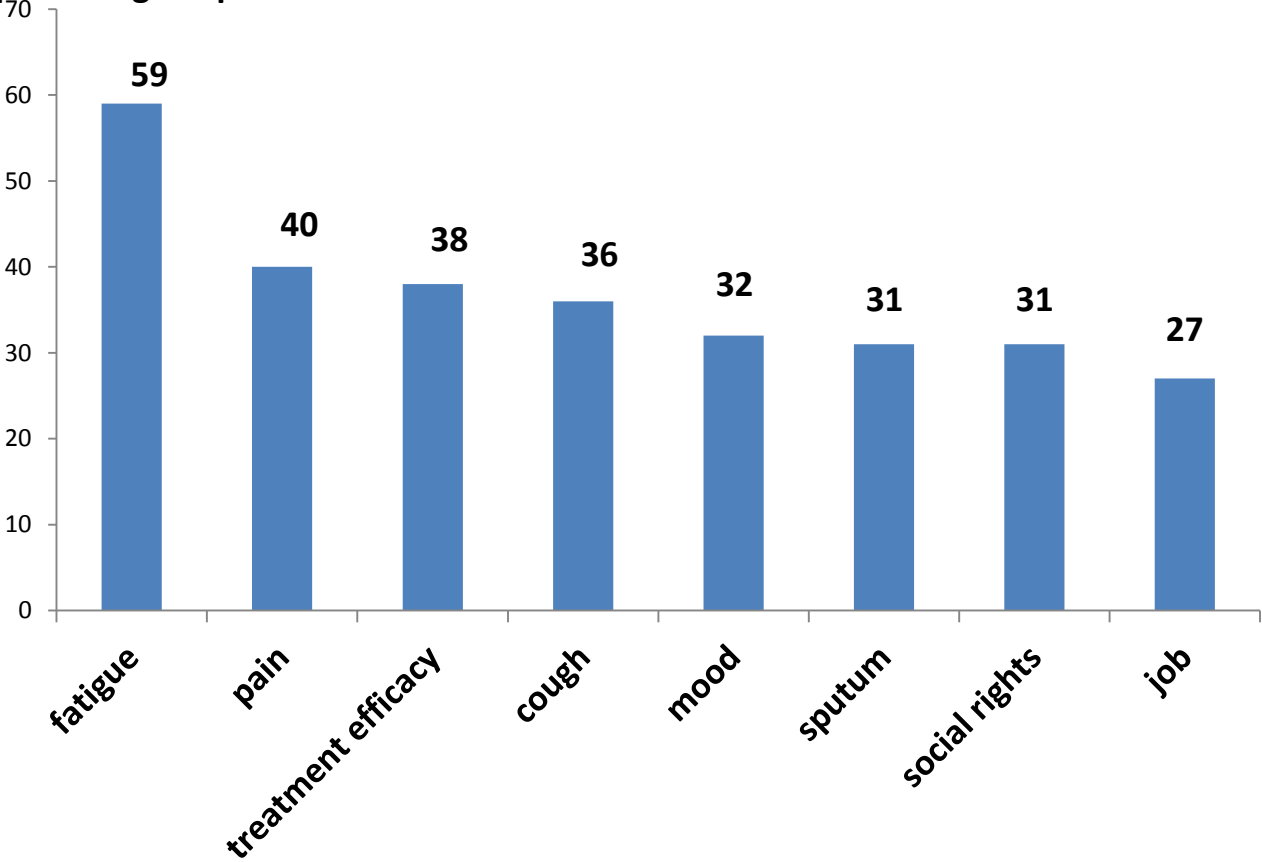
Patients who ticked at least one word in the topic

discomfort associated with CF
socio-professional life
treatment
psychological feeling
family life
organisation of the day
procreation
sexuality

Results – Frequently ticked words

percentage of patients

Words ticked
by > 25 %
of the patients



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

Des mots pour le dire

Date / /


Nom du médecin

Etiquette patient

Parmi **les mots** suivants, cochez ceux que vous aimeriez aborder lors de vos prochaines consultations avec le **médecin**. Parmi les mots cochés, entourez les **3 mots** auxquels vous donnez le plus d'importance ?


VIE SOCIALE ET FAMILIALE

- Famille
- Couple
- Enfants
- Amis
- Rencontres amoureuses
- Conduites à risque
- Avoir un enfant
- Parler de la maladie



RESSENTI PSYCHOLOGIQUE

- Moral
- Estime de soi, regard de l'autre
- Sentiment d'efficacité
- Motivation,
- Angoisse
- Ras le bol



LOISIRS

- Activités
- Sports
- Coûts
- Vacances, à l'étranger




TRAITEMENTS

- Régularité
- Arrêt
- Diminution (de la fréquence d'un soin)
- Logistique, approvisionnement
- Efficacité
- Effets secondaires
- Avancées médicales, recherche
- Évolution de la maladie et devenir
- Aide médicale à la procréation
- Transplantation

SYMPTÔMES LIÉS À LA MALADIE

- Douleurs
- Fatigue
- Qualité du sommeil
- Fuites urinaires
- Gaz
- Selles odorantes
- Constipation/diarrhée
- Crachats (gêne dans la vie sociale)
- Toux
- Mycoses



VIE SOCIOPROFESSIONNELLE

- Études/Travail
- Stage à l'étranger
- Absentéisme
- Droits sociaux
- Revenus
- Mutuelle
- Transports




VIE SEXUELLE

- Libido
- Image du corps
- Essoufflement
- Contraception
- Positions de confort
- MST/VIH
- Douleurs

ORGANISATION DE LA VIE QUOTIDIENNE

- Courses, tâches ménagères
- Temps de repos
- Planification activités/soins
- Hygiène
- Autonomie
- Ras le bol



PROJET

- Personnel
- Professionnel
- Autre



AUTRES

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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”.