

Characterization of CF Diagnosis Announcement Practices Following a Neonatal Screening in France

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INTRODUCTION

In France, CF is now part from 5 rare diseases routinely screened at birth. Professionals and patients all agree on the importance of the CF diagnosis announcement practices and of the necessity of their improvement. In 2003, the French CF Association "Vaincre La Mucoviscidose" published recommendations for those practices. In order to improve the quality of care, it was necessary to undertake an evaluation of the implementation of these recommendations to all concerned.

OBJECTIVES

Main objective: identify factors limiting or facilitating the application of the recommendations for diagnosis announcement after neonatal screening.

Secondary objectives: establish an inventory of the declared practices; check the conflicts between the practices and the recommendations; check the facilitating or limiting factors; analyze the difficulties of application of the recommendations.

MATERIAL

1) questionnaire in all involved centers (37) to collect the practices. It will resume each of the themes of the recommendations (who, to whom, how, what...?). Aim is to provide an overview of current practices
2) discussions (focus group - all the team - and individual interviews - representative of every involved profession) in some centers selected according to the degree of matching the regard to the recommendations. Aim is to list factors facilitating or limiting the application of the recommendations. The framework of the interviews will resume the classification proposed by Saillour-Glenisson a Saillour-Glenisson and Michel (*Individual and collective facilitators of and barriers to the use of clinical practice guidelines by physicians: a literature review*, *Rev Epidemiol Santé Publique* 51, 65-80, 2003)
Today, we are exposing the principal results of the questionnaires analysis (response rate: 34 of 37 centers, 92%)

PRINCIPALS PRACTICES MEETING THE RECOMMENDATIONS

The phone call

- Almost phone call for convocation are directed by the doctor who will see the family.
- The convocation is prompt after the phone call (69% within 24 hours; 0% more than 48h).
- Generally, no call is made during the weekend or in the evening.

The announcement

- The planning is homogeneous: welcome, test, announcement, short term schedule.
- Results are announced by the doctor who will take care of the child, alone (18%) or with a CF nurse (52%).
- Child is always present during announcement.
- 62% of physicians consider deliver the right amount of information.
- These topics are discussed during the interview: CF definition (72%); mode of transmission (76%); availability of the team (70%); importance of care (67%); normality of the baby (69%); constant progress in CF management (65%).
- Communication during the consultation seems to be "under control" and the behaviour of the physicians is adapted:

	Never	Sometimes	Often	Always
I call to ask questions.	0%	13%	22%	65%
I try to inspire confidence.	0%	10%	72%	17%
I don't know what to say.	94%	6%	0%	0%
I'm free especially for us.	0%	0%	9%	91%
I elude questions.	84%	10%	0%	6%
I let them take their time.	0%	3%	15%	82%

The 2nd consultation

- A second consultation is scheduled at the end of the announcement consultation, usually soon (66% within one week after).
- Parents are often contacted (phone call) between the two consultations.
- Social concerns, custody, hygiene, and diet are discussed most often in the second consultation.

THEMATIC REQUIRING MORE INVESTIGATIONS

• How perform better the phone call to the family for convocation?

Our CF center has written a call sheet, a kind of "memorandum" which also serves to take notes for the record. (Kerbrat M., Dirou A., Argouach S., Corre I., Pengam J., Gueganton L., Rault G. Procedure for diagnosis announcement of cystic fibrosis by a multidisciplinary team. 29th European CF Conference, 2006)

• Which place must be given to the general practitioner (GP)?

Some CF physicians (50%) contact the GP of the family before the consultation to explain the action to be taken in case of contact with parents. Others CF physicians contact GP only after diagnosis to advise on how to take care of the CF child.

• How better take care of parents during the sweat test?

Indeed, parents are waiting for about 1 hour. Centers are rare to propose occupations (coffee, tv ...) during this period of great anxiety.

• When are the best time to discuss the different announcements (eg.: hypofertility...)?

Generally, these issues are discussed at the request of parents (or patient) or when it becomes necessary. Nevertheless, it might be better that families hear this information earlier (again, in order to allow time for coping).

• How discuss the difficult issue of life expectancy?

Parents often approach this question at the announcement consultation. This issue is difficult for physicians, especially since the major medicalization of the death of a famous young French CF singer. 56% of the physicians choose to emphasize the progress of science and care, and do not give quantified answer. 38% give a quantified life expectancy but maybe a little more optimistic than commonly reported.

Physicians who choose not to give quantified expectancy are generally those who choose not to mention CF during the phone call.

• Which tools and councils for the communication with siblings, grand-parents...?

Half of the centers offer a meeting with the extended family (53%) or give some advices for communication (56%). One center offers a letter that parents could give around them and could use to discuss.

CONCLUSIONS

- 1) The announcement itself seems to be generally "under control" and in line with recommendations. Problems are essentially about the phone call:
 - double bind: ask parents to come soon but without worry them too much;
 - the disease is often mentioned, so parents want to learn more about disease, before the convocation, sometimes by all means;
 - difficulty to convene the 2 parents together;
 - demand for standardization on the part of physicians;
- 2) The period from the welcome in the CF center to the announcement needs to be more explored. Side of the child, practices are conform to the recommendations. But side of parents, practices are more heterogeneous. Parents are often left alone, without occupation, in enjoyable places. It would be necessary to explore their experiences during this period to consider an organization of a less anxiogenous waiting.
- 3) Available, attentive and empathic, physicians deliver an information more understandable and less invasive as possible. Parents are not overwhelmed with information and the time is given for coping. However, many physicians feel uncomfortable and embarrassed by the anger or inertia reactions of parents. So it's more the emotional relation than the informative communication which is difficult to manage.
- 4) The oldness and frequency of announcement practices have led to variations between. Those differences should be explored further.
- 5) The 2nd time of our study (focus group and individual discuss) should give us some precisions. Results will be presented at the next European Cystic Fibrosis Society Conference.

PRINCIPALS PRACTICES LESS CONFORM TO THE RECOMMENDATIONS

The phone call

- Words referring to CF are often mentioned during the phone call.

	Never	Sometimes	Always
Cystic Fibrosis	29%	50%	21%
Sweat test	41%	32%	26%
CF Center	35%	26%	9%

- Call duration reflects the difficulty of this time for physicians: 45% last more than 15 mn. The phone call is even longer than CF is evoked.
- The report of the phone call is generally oral (75%) or non-existent (30%).

The announcement

- An announcement to both parents together is not a requirement: the diversity of family status and the constraints of time constrain to deal with the circumstances. Only 16% of CF centers set an appointment when 2 parents are available.
- 50% of centers do not practice clinical exam of child and 50% had no long discussion with parents. These choices are related to organizational constraints or are real strategies.
- Discussion with parents may take place before getting the sweat test results (50%). 74% explain before the sweat test the exact reason for coming to CF center.
- 80% of the physicians do not introduce the whole team to the family this day.
- the announcement is rarely done in a dedicated or equipped place for that purpose (75% in the physician's desk).

The 2nd consultation

- Associative informations are not always done the day of the announcement.

	1st consultation	2nd consultation	later	on request
Details of associations	33%	43%	14%	10%
Details of other parents	6%	23%	29%	42%
Documentation (booklet...)	51%	30%	12%	15%

A PROPOSAL OF CENTERS TYPOLOGY

3 groups can be distinguished:

- "historic" centers (screening practicing since the 80's): they constitute a kind of referent nucleus;
- "high practice" centers (practicing screening since its generalization -2002-, but for more than 4 announcements per year);
- "low practice" centers (practicing screening since its generalization, for less than 4 per year or 40 since 2002).

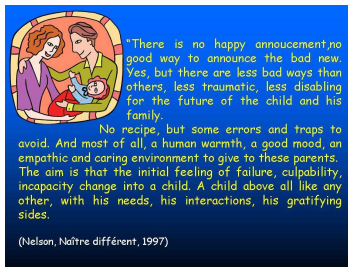
Several practices are influenced by this typology:

- Writing of an announcement procedure

	Yes/Current	Expected	No
Historic centers	40%	10%	50%
High practice centers	29%	43%	29%
Low practice centers	60%	10%	30%

- Time of the phone call: the more the center have a low experience, the more the call is long.
- Emotional control: physicians with the less frequent practices try more to mask their feelings.
- It's face to the parents anger that the less experimented are the more without.
- Auto-assessment "Do you believe your practices are conform to the good practices (cote to 0 - not at all - to 10)

	Mean
Historic centers	8.13%
High practice centers	7.90%
Low practice centers	6.93%
Mean for all	7.53%



Special thanks to:

- our financial partner

- all involved



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- all the CF teams who agreed to participate in our study