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Original article Provision of information on transplantation to cystic fibrosis patients and their relatives: Overview of French practices and recommendations



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ABSTRACT

Background. – How health-care professionals inform cystic fibrosis patients and their relatives about transplantation is not well known. Such information may not be provided in a timely or satisfactory manner. We conducted a survey about patient information practices among professionals from all French cystic fibrosis centers and transplant centers, to determine how they might be improved.

Methods. – This was a national, retrospective, multicenter, descriptive assessment of practices involving health-care professionals, transplant recipients and their relatives, and peer patients who are themselves transplant recipients. Questionnaires were developed by the French working group on cystic fibrosis patient education (GETHEM: Groupe éducation thérapeutique et mucoviscidose). At the end of the questionnaires, respondents were invited to suggest ways to improve the current process.

Results. – In all, 216 professionals, 55 patients, 30 relatives of these patients, and 17 peer patients responded to the questionnaires, which addressed topics in chronological order, from neonatal screening or later diagnosis of the illness to the time of the transplant, if one was performed.

Conclusions. – Study findings have allowed us to draft nine recommendations for professionals to improve patient information practices. A booklet now being prepared aims to facilitate the process for professionals, and e-learning modules are also forthcoming.

1. Introduction

There is uncertainty regarding the kind of information on lung transplantation provided to patients and their relatives by healthcare staff at French cystic fibrosis centers and transplant centers and how it is transmitted. A national study conducted between 2007 and 2010 showed that 40% of deceased cystic fibrosis patients who had not received a transplant either were never informed of the possibility or did not receive the information at the appropri-

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https://doi.org/10.1016/j.resmer.2019.12.002 2590-0412/© 2020 Published by Elsevier Masson SAS. ate time [1]. In 2013, a French national study on patient, carer, and physician attitudes about transplantation revealed potential obstacles to broaching the topic [2]. Health-care staff inertia and patient socioeconomic backgrounds and psychological profiles could have an effect on what kind of information is given and delay its transmission. The GETHEM group, including patients and professionals from various disciplines, conducted a survey to identify current information transmission practices and subsequently issue recommendations.

2. Materials and methods

The GETHEM study was a national, retrospective, multicenter, descriptive assessment of practices involving health-care professionals, transplant recipients and their relatives, and peer patients. (Peer patients are transplant recipients who meet with other patients considering a transplant, to share their experiences and

Abbreviations: GETHEM, Groupe éducation thérapeutique et mucoviscidose (French working group on cystic fibrosis patient education); HAS, Haute autorité de santé (French national health authority); FEV₁, forced expiratory volume per second.

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Table 1

Transplantation topics and different time points listed in the questionnaires submitted to patients/relatives and professionals.

Transplantation topics	topics Time points at which they may be addressed	
	For professionals	For patients and their relatives
criteria for initiating transplant preparation process components of pretransplant examination organ donation criteria for placement on transplant waiting list transplant wait time social aspects to consider when patient's health worsens intensification of treatments to improve patient's health means of transportation to facility when called in for the transplant surgery ICU monitoring immediately after transplant pain risks associated with transplantation interactions with relatives at time of transplant preparation for first visit home and return home post-transplant rehabilitation and resumption of a physical activity immediate complications of transplantation side effects of medication dietary precautions transplant recipients' desire to have children diabetes after transplantation kidney complications after transplantation expected benefits of transplantation psychological changes after transplantation academic or professional life after transplantation life expectancy after transplantation	Announcement of diagnosis of cystic fibrosis at time of neonatal screening Announcement of diagnosis of cystic fibrosis at later time	At the time of diagnosis
		center Upon registration at an adult cystic fibrosis
	During stage of illness when transplant is not yet appropriate	center During follow-up appointment
	During stage of illness when patient's health is deteriorating and you believe the transplant preparation process should begin	When patient's health worsens During a special pretransplant appointment
	When it is time to perform a pretransplant examination When it is time to put the patient on a transplant waiting list Other moments	When a pretransplant examination is indicated When patient has been placed on transplant waiting list During specific events Other moments

answer questions.) The study protocol was approved by French advisory committee on information processing in health research (CCTIRS).

2.1. Questionnaire design

The questionnaires were created by a GETHEM subgroup including physicians, physical therapists, nurses, patients, and patients' relatives. A methodologist assisted the subgroup in its work. The questionnaires were tested several times with professionals and patients, revised, and finally approved by the subgroup. Three different questionnaires, accessible by unique hyperlinks, were specifically designed for each category of respondent:

- professionals;
- patients and their relatives;
- peer patients.

Guided by the consensus document of the International Society for Heart and Lung Transplantation [3], professionals in the GETHEM group formally selected 11 medical conditions they believed should prompt initiation of the transplant preparation process : rapidly falling FEV₁, around-the-clock non-invasive

ventilation, reduced quality of life, supplemental oxygen requirement, FEV₁ below theoretical percentage, hypercapnia, increased need for intravenous antibiotic treatments, multiple hospitalizations, history of massive hemoptysis, history of recurrent pneumothorax with complications, and cachexia.

The information requested through the three different questionnaires is detailed below:

- questionnaire for professionals (duration \approx 45 min):
 - facts about professional, and frequency at which the professional provided patients and their relatives with information about transplantation,
 - type of information provided at different time points, from the announcement of the diagnosis to the time of the transplant. These different periods are presented in Table 1. For each time point, the professional was asked to specify;
 - whether information was provided routinely, in response to questions, or due to particular circumstances,
 - topics addressed, selected from a drop-down list (see Table 1),
 - how difficult, on a scale from 0 to 10, it was for them to provide information at that time point,

 whether, in his or her opinion, the information was communicated too early, at the right moment, or too late;

The questionnaire included open questions asking respondents for their opinions and suggestions regarding the informational materials used; how the task of transmitting information was shared and how this transmission was traced; the best times to provide information; and in summary, three positive and three negative aspects of the current process together with three suggestions for improvement.

- questionnaire for patients and their relatives (duration ≈ 30 min): Opinions on information received at different time points (see Table 1) before the transplant and on the informational materials used, and in summary, three positive and three negative aspects together with three suggestions for improvement;
- questionnaire for peer patients (duration ≈ 30 min): How peer patient was contacted, how meetings between peer patient and pretransplant patient were prepared and organized (i.e., peer and pretransplant patients alone or in company of professional; at the follow-up care hospital, in the patient's room, in a waiting room, in a corridor, or in a special meeting room), meeting duration, reasons for agreeing to meet, topics of discussion, how peer patient followed up on the meeting, peer patient's feelings about the meeting, and suggestions for improvement.

2.2. Study dates and participants

The study was conducted between July 2016 and June 2017. The following groups were invited to complete the questionnaires:

The approximately 450 health-care professionals (e.g., physicians, nurses, nurse's aides, psychologists, and physical therapists) employed by the 45 cystic fibrosis centers and 7 transplant centers across France. Note that 5 of the 7 transplant centers are in towns that also have a cystic fibrosis center. In these cases, the cystic fibrosis centers either serve an adult population and their staff also works at the neighboring transplant center, or they serve a pediatric population and are not associated with the transplant center. No cystic fibrosis centers serving both adults and children neighbor a transplant center.

The approximately 200 patients who received transplants within the two years preceding the start of the study), and for each of these patients, a single relative of their choice.

Peer patients, i.e., cystic fibrosis patients having received transplants (regardless of when) who—upon the request of staff at the cystic fibrosis or transplant center—elected to share their experience with other cystic fibrosis patients waiting for a transplant during the two years preceding the study.

During the enrolment period, the cystic fibrosis centers and transplant centers were sent e-mail reminders on 5 different occasions to increase the questionnaire response rate. Furthermore, when participants began but did not complete their questionnaires, they received automated reminders generated by the survey software (Survey Monkey).

Questionnaire responses were recorded by the survey software.

2.3. Data analysis

2.3.1. Quantitative data

Univariate descriptive statistics (numbers of people and percentages) were used for questionnaire responses. To help identify causes of failure to communicate information, two categories of professionals were distinguished in the analysis: "informers" and "noninformers."

• informers (*N* = 160) are professionals who communicate information about transplantation to patients or their relatives at least once a year, and as much as several times a week. This category

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Patient demographic data.

Sex		
Male	19	40.4%
Female	28	59.6%
Not reported	8	
Age		
[15–20]	2	4.3%
[20–30]	17	36.1%
[30–40]	17	36.2%
[40–50]	8	17%
[50–65]	3	6.4%
Not reported	8	
Occupational status		
Working	17	37.7%
Sick leave	3	6.7%
Disability	9	20.0%
Seeking employment	7	15.6%
In training	9	20.0%
Not reported	10	
Full-time work?		
Yes	16	48.5%
No	17	51.5%
Not reported	22	
Marital status		
Single	23	50.0%
Married	13	28.4%
In a civil union	2	4.3%
Cohabitation	6	13.0%
Other	2	4.3%
Not reported	9	
Number of children		
0	37	80.5%
1	6	13.0%
2	3	6.5%
Not reported	9	

includes 91.5% of the physicians, 75.9% of the nurses, and 64.7% of the psychologists and health-care social workers participating in the study;

noninformers (*N*=56) are professionals who discuss transplantation with patients or their relatives less than once a year, or never. Included in this category are 5 physicians, all working in a pediatric cystic fibrosis center that does not neighbor a transplant center; 17 nurses; 10 physical therapists; 10 nutritionists; 10 health-care social workers; 2 psychologists; 1 exercise therapist; and 1 secretary. Most of these professionals work with the pediatric population, in cystic fibrosis centers that do not neighbor transplant centers.

Qualitative data

Continuous thematic qualitative analysis of answers to open questions and suggested improvements was conducted.

3. Results

Questionnaires were completed by 216 (48%) of the 450 professionals expected to participate. Of these 216 respondents, most were nurses (29%) and physicians (27.2%), while others were physical therapists (14.7%), psychologists (10.1%), nutritionists (7.8%), health-care social workers (6%), or had other occupations (5.2%). Half were between the ages of 30 and 50, and 88% were women. Nearly 59% of the professionals worked at a cystic fibrosis center that did not neighbor a transplant center. In all, 55 patients, 30 relatives of these patients, and 17 peer patients responded to the questionnaire. Patient demographic data are given in Table 2. Among the 30 relatives, 16 were patients' mothers or fathers; 10, their spouses; 1, a nephew; and 3 did not declare their relationship. Of the 17 peer patients, there were 10 women and 7 men. Thirteen of the peer patients had jobs; 13 were in a relationship, while 4 were single; and 13 had no children, while 4 had one or more.

Table 3

Participating professionals were asked to state whether transplantation information should be provided to patients exhibiting any of the 11 medical conditions defined by the working group, which are listed above. Besides each condition are the percentages of "informer" and "noninformer" professionals, respectively, who deemed it should prompt discussion of transplantation with patients.

	11 medical conditions	Informers	Noninformers	Р
1	Rapidly falling FEV1	75%	69.6%	0.43
2	Around-the-clock noninvasive ventilation	73.1%	67.9%	0.45
3	Reduced quality of life	69.4%	73.2%	0.58
4	Supplemental oxygen requirement	69.4%	66.1%	0.64
5	FEV ₁ below theoretical percentage	65.6%	55.4%	0.17
6	Hypercapnia	63.1%	39.3%	0.02
7	Increased need for intravenous antibiotic treatments	62.5%	42.9%	0.01
8	Multiple hospitalizations	55%	32.1%	0.003
9	History of massive hemoptysis	51.3%	32.1%	0.006
10	History of recurrent pneumothorax with complications	40.6%	32.9%	0.26
11	Cachexia	28.8%	25%	0.59

Conditions for which P < 0.05 appear in bold. FEV1: forced expiratory volume per second.

Participating professionals were also asked to state whether transplantation information should be provided to patients exhibiting any of the 11 medical conditions defined by the working group (Table 3).

3.1. Perspectives of professionals, patients, and patients' relatives on transmission of information at different time points, from diagnosis to time of transplant

For the remainder of this article, data reported for professionals solely refer to the "informer" subgroup (N = 160). Additionally, percentages are given together with the number of positive responses over the total number of respondents (written as a quotient).

When information is provided at this point, 90% of the time it is in response to questions asked by patients (in case of later diagnosis) or their relatives that almost exclusively concern the expected benefits of a transplant. Half of the professionals describe transplantation as a distant possibility for treatment, necessary in the event of severe respiratory decline.

3.2. Upon registration at new cystic fibrosis center or admission to adult cystic fibrosis center

Professionals were not asked about this period. Information was received by 49% (22/45) of patients and 42% (10/24) of relatives. Overall, 77%(17/22) of patients and 67%(6/9) of relatives believe an appropriate amount of information is provided at this time. Finally, 75%(18/24) of the patients and all (7/7) relatives think it is an appropriate time to receive information.

For the next four time points, topics and frequencies at which they are discussed are presented in Fig. 1 for professionals, Fig. 2 for patients, and Fig. 3 for relatives.

3.3. During stage of illness when transplant would not be appropriate

For 54% of professionals (55/101), this is a difficult time to inform patients, yet 54% (54/101) also believe it is the right time to do so, while 39% (39/101) say they do not know whether it is the appropriate time. Information was received by 87% of patients (45/52) and 78% (21/27) of relatives at this time. The information was almost always provided by a physician: two-thirds of the time at the physician's initiative and the rest of the time in response to patients' questions. Overall, 91% (39/43) of patients and 83% (15/18) of relatives believe an appropriate amount of information is provided at this time point. Finally, 83% (35/42) of the patients and all (16/16) relatives feel it is a good time to receive information. 3.4. During stage of illness when patient's health is deteriorating and professional believes the transplant preparation process should begin

At this point, 61% (73/119) of professionals provide information "routinely," 32% (38/119) do so "in response to questions," and 28% (33/119) "during an acute episode." Furthermore, 39% (47/121) think it is difficult to provide information at this time point, 57% (69/121) deem it is the right time, but 11% (13/121) believe it is too late. (The denominators—i.e., 119 and 121—differ as the number of responses given varied between questionnaire sections.) Finally, 79% (37/47) of patients and 71% (17/24) of relatives received information at this time—from a professional in 85% of the cases and from a transplant recipient in 15% of the cases. The information is generally communicated by a physician—42% of the time in response to patients' questions. It is the opinion of 89% (32/36) of patients and 87% (14/16) of relatives that an appropriate amount of information is provided. According to 91% (30/33) of patients and all (17/17) relatives, this is a good time to provide such information.

3.5. When a pretransplant examination is indicated

Information is "routinely" provided by 80% (105/131) of professionals at this point. Moreover, 80% (32/40) of patients and 59% (13/22) of relatives received information at this time—80% of the time from a professional (usually a physician but sometimes a psychologist) and 20% of the time from another patient.

3.6. When being placed on a transplant waiting list

At this time point, information is "routinely" given by 81% of professionals (81/100). Information is received at this time by 71% (29/41) of patients and 72% (18/25) of relatives. It was provided to the patient by a professional (usually a physician) in 88% of the cases and by another patient in 12% of the cases.

Informational materials were reportedly not used by 86% (137/160) of professionals during their face-to-face discussions with patients, though 44% said they did use them at later points, following these discussions. These materials were always brochures—either nationally distributed by associations or specific to the center—and patients considered them suitable. Profession-als also mentioned other patient information channels, including support groups, television programs, and association meetings. Patients and their relatives also stated they received information from other sources, including transplant recipients, online publications, and social networks.



Fig. 1. Topics routinely addressed by professionals at the following four time points (corresponding to four shaded bars—from darkest to lightest—next to each topic listed in the figure):when it is time to put the patient on a transplant waiting list; when it is time to perform a pretransplant examination; during stage of illness when patient's health is deteriorating and you believe the transplant preparation process should begin. During stage of illness when transplant is not yet appropriate. Colors indicate different categories of topics: green for pretransplant, grey for peritransplant (i.e., immediately before and immediately after), orange for medication and its consequences, and blue for psychosocial aspects. For example, the first topic—"criteria for initiating transplant preparation process," in the "pretransplant" category (green)—is addressed by 28% of professionals "when it is time to put the patient on a transplant waiting list" (corresponding to first of four shaded bars).

3.7. Responses of 17 peer patients

Of the 17 peer patients, 10 were asked to share their experience by a nurse, 5 by a physician, and 2 by a psychologist. Interviews were briefly prepared in half of the cases, the professional asking the peer patient to speak positively about transplantation.

Here are two remarks, by way of illustration:

- "I was asked to speak especially about life after the transplant operation, and the happiness it could bring."
- "I was told that the patient was stressed and that she needed reassurance."

According to their responses, 76% (13/17) of peer patients received little or no support from the health-care team. In 65%



Fig. 2. Topics addressed by professionals, according to patients, at following four time points (corresponding to four shaded bars—from darkest to lightest—next to each topic listed in the figure): when being placed on a transplant waiting list; when a pretransplant examination is indicated; during a special pretransplant appointment; when patient's health worsens. Colors indicate different categories of topics: green for pretransplant, grey for peritransplant (i.e., immediately before and immediately after), orange for medication and its consequences, and blue for psychosocial aspects. For example, according to patients, the first topic—"criteria for initiating transplant preparation process," in the "pretransplant" category (green)—is addressed "when it is time to put the patient on a transplant waiting list" (corresponding to first of four shaded bars) in 31% of all cases.

(11/17) of the cases, peer patients had direct, face-to-face interviews, while others communicated remotely. Of the face-to-face interviews, 47% (8/17) took place in the patient's hospital room, 18% (3/17) in a waiting room, 6% (1/17) in a corridor, 6% (1/17) in a meeting room, and 6% (1/17) in an examination room. The only parties present were the patient waiting for a transplant and the peer patient in 88% (15/17) of the cases. In the remaining cases, a professional was also there. Among the 17 peer patients, 15 were ready to speak with patients again, 8 said they personally benefited from the experience, and all thought the interviews were very useful for the patients they spoke with. Peer patients were never invited to discuss their interviews after their conclusion. Of the 10 who had further discussions with patients they had met, 7 did so over blogs or social networks.

Suggestions for improvement collected through the questionnaires are presented in Table 4. They may serve as signposts for professionals.

4. Discussion

This study aimed to improve how professionals informed patients. The large number of professional respondents (216/520) suggests the level of interest it garnered. The ability to stop and return to the online questionnaire as needed, and to access it from any computer using a unique link, as well as the questionnaire's checkbox format, may all have contributed to the high response rate.



Fig. 3. Topics addressed by professionals, according to relatives, at following four time points (corresponding to four shaded bars–from darkest to lightest–next to each topic listed in the figure): When being placed on a transplant waiting list; When a pretransplant examination is indicated; During a special pretransplant appointment; When patient's health worsens. Colors indicate different categories of topics: green for pretransplant, grey for peritransplant (i.e., immediately before and immediately after), orange for medication and its consequences, and blue for psychosocial aspects. For example, according to patients' relatives, the first topic—"criteria for initiating transplant preparation process," in the "pretransplant" (corresponding to first of four shaded bars) in 32% of all cases.

4.1. Participation in survey

Fifty-five out of approximately 200 patients transplanted during the 2 years preceding the study responded, which is also a satisfactory response rate. The choice to limit participation to transplanted patients, rather than all cystic fibrosis patients in France, was deliberate: we sought their unique perspective. Furthermore, the 2-year requirement aimed to ensure that participants' responses regarding information received drew on fresh memories. Each participating patient was asked to have one relative complete a special questionnaire, but only 30 relatives, rather than the 55 expected, did. Hence the response rate among relatives was lower. The peer patients referred to in this study were transplant recipients that had been approached by cystic fibrosis center staff and asked to share their experience with pretransplant patients, answering any questions they might have. The choice of these peer patients was partly based on age, sex, life history, and the staff's impression that both parties were psychologically prepared. Another criterion was presence at the cystic fibrosis center or transplant center on the same day as the patient awaiting transplantation. As there are no formal lists of patients willing to share their experiences, nor established criteria for specifically designating them "peer patients," they are not easily identified by staff, which may explain why we only received 17 peer patient responses. This compels us to reflect on the definition of the peer patient in France, and on the support peer patients might receive, through training or their relations with health-care staff.

4.2. Volume and timing of patient information

Generally speaking, professionals provide a lot of information, especially as patients near the start of the transplant preparation

Table 4

Suggestions for improvement culled from questionnaire responses.

Appropriate time	Respond to requests from patients or their families; invite questions
	Provide information ahead of time, well before the patient's state of health requires, even if there is no emergency
	Make transmission of information routine and part of long-term follow-up (e.g., provide information upon diagnosis,
	when registering at a cystic fibrosis center, and when switching to adult care)
	Provide information through patient education programs
	Make more detailed, easily accessible informational resources and materials (e.g., brochures and videos) available to
	patients
	Disseminate information during gatherings held by the association Vaincre la Mucoviscidose (Defeat cystic fibrosis)
	and national organ donation events
Appropriate manner (setting,	Find a calm place to talk, free of disturbances
attitude, resources, etc.)	
	Strengthen the doctor-patient relationship and build patients' trust in their physicians, who often know them and
	their families well and have monitored and treated their illness over a long period
	Speak candidly about the subject, without fear
	Do not glorify transplantation, but remain objective; present risks and benefits, being honest, frank, and transparent,
	but clear and comprehensible
	Enhance interpersonal skills of health-care professionals
	Support patients when confronted with misinformation about transplants relayed by the media, websites, and social
	networks
	Give more information about post-transplant considerations (e.g., complications and follow-up)
	Provide information to patients' relatives too, and involve them in the patient care process
Adaptation to patient	Take into account the conceptions that patients and their relatives have of transplantation
	Assess the extent to which patients are able to project themselves into the future.
	Opt for face-to-face two-way discussions between the patient and, preferably, the coordinating physician, adapting
	content and remaining attentive
	Take the time needed to provide the information, even if several discussions are needed, considering the patient's
	psychological state and degree of comprehension; choose the "right moment"
	Consider the patient's degree of intellectual curiosity, interest in understanding the illness, and educational or
	intellectual level, as well as the extent to which family and friends are invested
	Take into account the many risk factors—and outright contraindications—for transplant complications, e.g.,
	noncompliance, psychiatric disorders, and great distance between home and cystic fibrosis center
Staff measures	Provide cystic fibrosis center professionals with better training on transplants and how to speak about them with
	patients; create a booklet, checklists, and interview guides
	Enhance multidisciplinary teamwork, improving communication between the professionals involved
	Strengthen ties between cystic fibrosis centers and transplant centers; promote the exchange of information and
	practices between centers; have cystic fibrosis center professionals visit transplant centers
	Encourage meetings between patients awaiting transplants and transplant recipients; share written or filmed
	testimonials of lung transplant recipients
	Improve traceability of information for patient file
	· · ·

process. Some were nevertheless aware they were late in informing patients and felt disappointed about this. As information is often informally exchanged between professionals, there is need for greater traceability.

Patients and their relatives want to be informed earlier, well before progression of the disease requires it. They believe it is important that professionals take time, show care and empathy, adapt their message to the patient at hand, and use informational materials. If addressing patients for whom a transplant is not yet indicated, professionals seldom discuss treatment intensification as a means of considerably delaying the need for a transplant. Even when they do, this message does not seem to be heard by patients. This does not reflect a lack of knowledge on the part of healthcare professionals, but rather emotional discomfort and inertia. To enhance the quality of the relationship between patients and health-care professionals, the latter must develop empathy, compassion, and attentiveness.

Half of the participating professionals indicated it was difficult, but important, to inform patients during the stage of the illness when a transplant would not be appropriate, while 39% said they didn't know if that was the right time or not, especially when the patient asked no questions. These responses reveal that discussing such a delicate topic is a challenge for health-care staff, who need to be receptive to patients' emotions. It also underscores the importance of ensuring that all professionals concerned are familiar with the fundamentals of transplantation and are trained in psychosocial support, motivational interviewing, and the analysis of professional practices. When transplantation is not yet appropriate, it is important to provide comprehensive information, without going into details, so that patients know that this is a therapeutic option.

At each time point, in 80% or more of the cases (depending on the period in question), information is provided not only to patients but also to their relatives. Hence the latter are indeed taken into account. Much information is provided at the start of the transplant preparation process. Professionals say they mostly address the pretransplant stage, while patients and their relatives say they receive information regarding the pre-, peri-, and post-transplant periods. As the time of transplantation approaches, the amount of information received by patients' relatives increases. The responses of peer patients show they wanted to provide patients awaiting transplants the same support they had received. Peer patients emphasize how rewarding it is to meet with pretransplant patients but also express their fears of scaring them and how hard it is to revisit their own stories. Though informational materials are seldom used by professionals, patients and their relatives consider them very useful.

4.3. Knowledge about transplantation differs between informers and noninformers

We see that higher percentages of informers recognized medical conditions that should prompt initiation of the transplant preparation process (Table 3). For both informers and noninformers, the medical conditions least likely to prompt transmission of information to patients were a history of massive hemoptysis, a history of repeated complicated pneumothorax episodes, and cachexia. The increased need for intravenous antibiotic treatments and hypercapnia were unfamiliar indications for all professionals. In no category of health-care staff did respondents indicate all eleven conditions, even the most well known, like rapidly falling FEV₁ and noninvasive ventilation. This reflects a need to further educate health-care staff about medical indications for transplantation, even if the role of certain professionals is not so much to help provide patients with specialized information as to understand it—to ensure their own communication is consistent with physicians' messages to patients.

Professionals who responded often indicated the importance of addressing the expected benefits of transplantation at many time points. In contrast, psychological effects; organ donation; and the short-, medium-, or long-term future of a transplant recipient are topics rarely broached at any time point. Moreover, while associated treatments and their side effects are touched upon, complications like diabetes and kidney problems hardly are.

4.4. Transmission of information

Means of informing patients about transplants are seldom presented in the international literature. In 2015, the HAS issued national recommendations regarding patient information on kidney transplants [4]. Among these, the following are general enough to also apply to lung transplants for patients with cystic fibrosis:

- honor patients' choices and priorities about life and lifestyle;
- involve a diverse range of professionals in the transmission of structured information through a patient education program;
- provide patients with informational documents and URLs for online information.

The same recommendations were made by participants in our study. However, unlike kidney transplants, which can be put off by recourse to dialysis, there is no medical means of greatly postponing a lung transplant, which complicates the patient information process. Deteriorating respiratory function, complications like pneumothorax or hemoptysis, or the development of other medical conditions might be appropriate moments to provide information.

Most studies conducted among patients with cystic fibrosis report a lack of information [5,6] and the need for patients and health-care professionals to engage in shared decision-making [7,8]. The patient education process is centered on patient needs: the information provided depends on the specific patient, disease stage, and questions the patient has—or doesn't—about transplantation. Some professionals in our study said they lacked needed or current knowledge to provide patients with high-quality information. As one stated, "we don't give information, or we give bad information, and often we give it when it's too late." Continuing education is needed for health-care staff. A booklet that reviews the minimum a professional should know in order to feel more at ease speaking to patients and answering their questions about transplants is now being drafted, and e-learning modules are also being prepared.

4.5. Nine good practices approved by GETHEM

Many responses to open questions were received. They facilitated interpretation of quantitative data and were a source of many ideas for improvement (Table 4). A review of all responses from professionals, patients and their relatives, and peer patients allowed us to create a guide presenting the following patient information recommendations for professionals:

- throughout the period following announcement of the diagnosis, the questions of patients and their relatives must be answered, but detailed knowledge is not needed;
- when a patient first registers at an adult cystic fibrosis center, or switches to another cystic fibrosis center, and is assigned a new

supervising physician, it is appropriate to determine patients' current attitudes towards transplantation and address any questions they might have, depending on their state of health;

- patients and their relatives must regularly be given the opportunity to pose any questions related to transplantation;
- rapidly falling FEV₁ should be a red flag for health-care staff, signaling they should inform patients about transplantation;
- professionals must provide information earlier in the course of patients' illness, as soon as the very first signs of deteriorating health are identified, which underscores the importance of their detection. To reach a decision with the patient regarding treatment intensification, the patient should receive information on transplantation and be told intensification postpones the need for a transplant;
- information provided must account for the patient's state of health and the availability of new therapies;
- discussion should take place in a calm setting free of disturbances;
- the health-care professional must be attentive and empathetic towards patients, while remembering that perception of time differs between patients and those who treat them;
- beyond addressing expected benefits of a transplant, patient information should touch on psychological and social aspects, the desire to have children, the conditions of pregnancy before and after transplantation, the impact on patients' professional lives, and relevant social assistance program developments. The importance of psychosocial factors has already been pointed out in a study that sought to identify the educational needs of patients for whom transplantation is an option [9].

These recommendations largely parallel recent statements from Canadian and American foundations developing programs for the transition to transplantation [10,11].

4.6. Limits of study

Our study has several limitations. Not all professionals responded to the survey, the estimated response rate being 48%. The transplant patients who responded do not represent the entire population of transplant patients, and only 30 of the 55 relatives asked to participate did so. Peer patients were recruited by cystic fibrosis center professionals, which also introduces bias, and only 17 responses were received—including 9 from Nantes University Hospital (CHU de Nantes), the main study center. In addition, professionals, patients, and patients' relatives were questioned regarding time points that were not all described in the same way. Furthermore, patients and their relatives were asked about more time points than professionals, making it difficult to compare responses. And finally, respondents may have found the large number of questionnaire topics somewhat tiring.

5. Conclusions

This study evaluated trends in the transmission of information on transplantation to patients and their relatives. It confirms that much information is given, yet sometimes too late and not enough. The information patients and their relatives report receiving and the information professionals think they have provided are not always identical. These observations have prompted the above recommendations for improving the patient information process. Now the goal is to implement them at all French cystic fibrosis centers and transplant centers and subsequently evaluate their impact. The present study already contributes to raising professionals' awareness about the sensitive subject of transplantation.

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Disclosure of interest

The authors declare that they have no competing interest.

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References

- [1] Martin C, Hamard C, Kanaan R, Boussaud V, Grenet D, Abély M, et al. Causes of death in French cystic fibrosis patients: the need for improvement in transplantation referral strategies! J Cyst Fibros 2016;15:204–12, http://dx.doi.org/10.1016/j.jcf.2015.09.002.
- [2] Marchand C, Salhi L, Le Rhun A, Ravilly S, Danner-Boucher I, Gagnayre R, et al. Motivations et freins à la greffe chez patients, aidants et médecins dans la mucoviscidose [Perceptions of cystic fibrosis patients, patient relatives and physicians: Barriers or motivations to lung transplantation]. Rev Mal Respir 2013;31(3):237-47, http://dx.doi.org/10.1016/j.rmr.2013.06.004.
- [3] Weill D, Benden C, Corris PA, Dark JH, Davis RD, Keshavjee S, et al. A consensus document for the selection of lung transplant candidates: 2014–an

update from the pulmonary transplantation council of the international society for heart and lung transplantation. J Heart Lung Transplant 2015;34:1–15, http://dx.doi.org/10.1016/j.healun.2014.06.014.

- [4] HAS. Recommandation de bonne pratique. Transplantation rénale. Accès à la liste d'attente nationale. [Recommended best practice. Kidney transplantation. Access to national waiting list.]. Saint-Denis: 2015. https://www.has-sante.fr/portail/upload/docs/application/pdf/2015-12/rbp.recommandations.greffe_renale_vd_mel.pdf.
- [5] Sawicki GS, Sellers DE, McGuffie K, Robinson W. Adults with cystic fibrosis report important and unmet needs for disease information. J Cyst Fibros 2007;6:411-6, http://dx.doi.org/10.1016/j.jcf.2007.03.004.
- [6] Moloney S, Cicutto L, Hutcheon M, Singer L. Deciding about lung transplantation: informational needs of patients and support persons. Prog Transplant 2007;17:183–92.
- [7] Vandemheen KL, Aaron SD, Poirier C, Tullis E, O'Connor A. Development of a decision aid for adult cystic fibrosis patients considering referral for lung transplantation. Prog Transplant 2010;20:81–7.
- [8] Stacey D, Vandemheen KL, Hennessey R, Gooyers T, Gaudet E, Mallick R, et al. Implementation of a cystic fibrosis lung transplant referral patient decision aid in routine clinical practice: an observational study. Implement Sci 2015:10, http://dx.doi.org/10.1186/s13012-015-0206-4.
- [9] David V, Feldman D, Danner-Boucher I, Rhun AL, Guyomarch B, Ravilly S, et al. Identifying the educational needs of lung transplant recipients with cystic fibrosis. Prog Transplant 2015;25:18–25, http://dx.doi.org/10.7182/pit2015526.
- [10] Cystic Fibrosis Canada. Developing national standards in Canada to successfully transition transplant patients with cystic fibrosis. Toronto: c2019. https://www.cysticfibrosis.ca/our-programs/healthcare/transition-totransplant.
- [11] Cystic Fibrosis Foundation. Talking about a lung transplant. Bethesda. https://www.cff.org/Life-With-CF/Treatments-and-Therapies/Lung-Transplantation/What-to-Consider-Regarding-a-Lung-Transplant/How-Is-a-Lung-Transplant-Initiated/.