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Healthcare Providers Perception of Therapeutic Patient Education Efficacy According to Patient and Healthcare Provider Characteristics

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Objectives. Therapeutic Patient Education (TPE) improve numerous health and psychological outcomes in patients with chronic diseases. However, little is known about what makes a TPE intervention more effective than another one. This study aims to identify in healthcare professionals the perceived determinants of TPE efficacy at the individual level.

Methods. Semi-structured individual interviews have been conducted with Healthcare professionals (HCP, n=28, including 20 nurses) involved in TPE programs (n=14) covering various chronic conditions (kidney and cardiovascular diseases, chronic pain, diabetes, etc.). A thematic content analysis following an inductive approach was used (Nvivo.11 software).

Results. Five themes were retrieved for patient characteristics: understanding and education, personality, readiness and motivation, social environment, and misinformation and beliefs. Four themes were retrieved for HCP's characteristics: medical knowledge, appropriate attitude and relational skills, pedagogical skills, and training.

Discussion. Patient personality is rarely discussed in the literature. Patients who are introverted, lack curiosity or are not compliant might benefit from specific TPE practices or formats. All these potential determinants regarding patients and HCP should be routinely assessed in future studies about TPE efficacy to understand precisely what makes an intervention successful.

Keywords. Chronic illness; Health Education; Patient Education; Qualitative Research; Healthcare Providers

1. Introduction.

In Western countries, the proportion of years lived with disability is increasing and the transition to non-fatal outcomes as the dominant source of burden is occurring rapidly due to the ageing of the population and the increase in prevalence of non-communicable chronic diseases ¹. In Europe, non-communicable chronic diseases account for nearly 86% of all deaths and 77% of the disease burden, thereby placing a high strain on health systems and individuals' quality of life ².

Therapeutic patient education (TPE) refers to "educational activities essential to the management of pathological conditions, managed by health care providers (HCPs) duly trained in the field of education, designed to help a patient manage their treatment and prevent avoidable complications, while keeping or improving their quality of life" ³. In other words, TPE is designed to help patients and their families understand the disease and the treatment, cooperate with HCPs and maintain or improve quality of life.

TPE has been found effective for improving numerous health and psychological outcomes in patients with chronic diseases ^{4,5}. It has been shown that TPE increases knowledge ⁶, medication adherence ^{6,7} and disease control ⁸ in patients with various chronic diseases. For instance, TPE has been associated with better knowledge in patients with cardiac issues ⁹, diabetes ¹⁰, asthma ¹¹, hemodialysis patients ¹² and patient with a stoma ^{13,14}.TPE also favors glycemic control in patients with diabetes ^{10,15}, better interdialytic weight gain in hemodialysis patients ¹², shorter postoperative hospital stay in patient with a stoma ^{13,14} and fewer hospital readmission after heart surgery ¹⁶. Finally TPE has been associated with less depressive symptoms, more well-being, quality of life and psychological adjustment in patient with diabetes ¹⁰, hemodialysis patients ¹² and patients with a stoma ^{13,14}

However, there is growing concern about the lack of adequate description of TPE interventions ^{4,5,17–19}. The French national health authority highlighted that specific TPE interventions are mostly compared to usual care but not to other TPE interventions ⁴. Thus, little is known about what might make a TPE intervention more effective than another one ^{4,5,17–19}. According to Conn ¹⁷, there is a "black box" phenomenon surrounding TPE interventions. TPE effectiveness might change according to various intervention attributes (content, duration, group or individual sessions, educational tools, use of information technology, professional training etc.) patient characteristics (motivation, social background, needs and expectations etc.) and illness features (severity, duration, comorbidity, treatment etc.) ⁴.

Little is known about the patient characteristics that might affect TPE effectiveness. Broadly speaking, social inequality exists in access to health information and education ^{20,21}. Recently, there has been growing interest in health literacy in patients and its association with health outcome ^{22–24}. People with low level of heath literacy

might have a hard time understanding and memorizing complex health information that uses medical terminology ²³. Tailoring educational and behavioral interventions to the patient level of heath literacy can increase various outcomes such a knowledge about hypertension or disease control in diabetes ²⁴. TPE interventions should at least take universal precautions to reduce the complexity for all patients ²⁵ and consider tailoring content to health literacy levels of patients ²⁴. We have much less evidence regarding patients' cultural background. Some studies suggest that patients from minority groups might benefit from culturally appropriate TPE interventions designed to match their values, practices and language and using educators from the same culture ^{26,27}. Moreover, training HCPs to consider the cultural context of their patients might improve patient outcomes such as glycemic control, food practices and diabetes knowledge ²⁸.

Regarding HCP characteristics, the French national health authority states that TPE interventions should be offered by a team of trained HCPs (nurses, physicians, dieticians etc.) ⁴. However, many studies do not provide HCP characteristics ¹⁹. Nearly half of French HCPs working with patients with diabetes reported that the lack of training of their team was a barrier to effectively provide TPE ²⁹. However; the skills needed to provide effective TPE seem to be insufficiently defined ³⁰. Svavarsdóttir et al. ³¹ reported the skills and knowledge needed to be competent in TPE for coronary heart disease according to HCPs: They should have 1) updated knowledge about the chronic illness and TPE; 2) high clinical experience and dedication in TPE, and 3) advanced communication skills to provide patient-centered, empathic and motivating TPE. Similarly, Hwang & Kuo ³² in a concept analysis of 25 articles dealing with competency in TPE, found that HCP should have a high level of professionalism (knowledge, skills and information searching) and be skilled in teaching (methods and procedure). Finally, they must be empowering (build partnerships and motivate discourse).

This study is part of a larger project called Classification of Patient Therapeutic Education Programs Components (CONCErTO; ClinicalTrials.gov NCT02717182). CONCErTO aims to identify, via qualitative investigation with HCPs, the organizational, pedagogical, psychosocial and medical components that affect the outcomes of TPE programs. According to May's normalization process theory ³³, various levels of analysis exist, ranging from the micro level (individual characteristics), meso level (the TPE program itself, patient group, patient families etc.) and macro level (healthcare policies, cultural context etc.). In this paper, we explored the micro level (patient and HCP characteristics).

2. Methods

2.1. Sample and Interview

Semi-structured interviews were conducted with HCPs involved in 14 TPE programs. Programs were chosen among a list of 136 programs authorized by regional health authorities. We excluded 23 TPE programs directed to children, people with spleen diseases and psychiatric disorders.

To obtain a diverse sample (maximum variation sampling ³⁴) we selected TPE programs (n=14) that covered various chronic diseases (See Table 1) Moreover, selected TPE programs were hospital-based (n=9) or not-hospital-based (n=5) and located in urban (n=10) or rural (n=4) areas. Twenty-eight participants have been recruited.

A meeting with HCP involved in each TPE programs was scheduled in their own facilities. We interviewed all HCPs who were present on the day of the interview. The researchers did not have any relationship with HCPs before the study. All HCPs agreed to participate after a short presentation of the CONCErTO project. All participants gave their written and oral consent. Interview (face-to-face) duration was about 1 hour. Interviews were recorded on an audio device and fully transcribed. Transcription of interviews were nearly 6200 words long on average (M=6189, SD = 1769, min-max=2875-9950). Field notes were not taken. None of the interviews were repeated and transcripts were not returned to participants for comments.

INSERT TABLE 1

The interview guide was constructed during three meetings by a clinician/epidemiologist (AR, MD, female, coordinator of a TPE program in rheumatology), a psychologist (LR, PhD, female) and a sociologist (JK, PhD, female, coordinator of a TPE transversal hospital unit). HCPs were asked to describe their TPE practices and identify organizational, pedagogical, psychosocial, medical or contextual elements that may affect the outcomes, participation and sustainability of the program. In other words, HCPs were encouraged to speak freely about factors of success or difficulty in the TPE, based on their experience (see Table 2).

Semi-structured interviews were conducted by a psychologist (LR) and a sociologist (JK) from April 2016 to May 2017. Interviewers had significant experience in conducting qualitative research (>10 years). No one else was present besides the participant and the researcher (JK or LR) during the interview.

INSERT TABLE 2

2.2. Ethical Considerations

The protocol was approved by a regional ethics committee (Comité de Protection des Personnes [CPP] Sud-Est I) in February 2017 (no. ID-RCB: 2017-A00247-46; no. CPP: 2017-12). All participants gave their written and oral consent. *2.3. Data analysis and Rigor*

Qualitative data are reported according to COREQ criteria. 35

Saturation occurs when no further meaningful information is added by new participants ³⁸. To achieve data saturation, Psychologist (LR) conducted interviews with HCPs until the information redundancy point was reached. Sociologist (JK) then conducted three more interviews to ensure data saturation. Saturation was achieved with 28 interviews.

After a careful and open-minded reading of transcriptions, categories for thematic content analysis were developed (inductive approach) using the Nvivo.11 software. We followed a general inductive approach to identify themes from the participant's discourse ³⁶

First a health psychologist (LR) developed categories with the first three interviews. Then, the categories were refined with two other interviews during a meeting by a a sociologist (JK) and a clinician/epidemiologist (AR). All themes and subthemes were defined and discussed to triangulate the perspectives of psychology, sociology, and clinical and public health. In this type of triangulation, researchers provide different insights for a deeper and broader understanding of findings.

Then, six interviews were analyzed by both a health psychologist (LR) and a trained psychology student (master degree) (JV, female). Disagreements between the two coders were resolved by discussion. In case of persistent disagreement, resolution was obtained by discussion with a third researcher. A document describing the categories and elements to be included in each category was created and revised during the coding process. Cohen's kappa coefficient has been computed to check for agreement between the two coders and was satisfactory (0.89) ³⁷. Finally, the psychology student (JV) encoded the remaining qualitative data. Participants did not provide feedback on findings.

According to May's normalization process theory ³³, various levels of analysis exist, ranging from the micro level (individual characteristics), meso level (the TPE program itself, patient group, patient families etc.) and macro level (healthcare policies, cultural context etc.). In this paper, we explored the micro level (patient and HCP characteristics) in detail.

3. Results

3.1. Sample description

Most of the 28 participants were nurses (n=20) and about half were older than 51 years (n=13) and had a moderate TPE experience (4-9 years) (n=14) (See Table 1)

3.2. Patient characteristics thought to be associated with TPE efficacy

With a thematic content analysis of participants' speech, five themes were derived regarding patient characteristics affecting TPE efficacy (Table 3): (P1) understanding and education; (P2) personality; (P3) readiness and motivation; (P4) social environment; and (P5) misinformation and beliefs. Quotes are available in Table 3.

INSERT TABLE 3

First, patients need to be able to understand and integrate TPE (P1). HCP reported that some patients have a difficult time understanding information because they have cognitive disabilities, low literacy or numeracy skills or because French is not their native language. Some patients are not offered TPE because of their low literacy level. Nevertheless, some HCPs stressed that patients should not be denied such support. HCPs were aware that they needed to tailor TPE according to the literacy levels of patients by using simpler vocabulary and providing essential information. Conversely, patients who are highly educated may also need tailoring with more detailed and scientific explanations. Some might feel that they have nothing to learn from TPE.

According to HCPs, patients' personality (P2) is an important factor affecting TPE efficacy. First, patients who are introverted might have a difficult time, especially in group sessions, for instance, because they might fear judgment. In contrast, patients who are extroverted may endanger the group dynamics because they can "suffocate" other participants and monopolize the discussion. Second, patients have to be curious, open-minded and wish to expand their knowledge in order to truly benefit from TPE. Patients who are self-centered might lack such curiosity and openness. Finally, patients' level of compliance might be important to consider. Indeed, patients who are rebellious might be difficult to handle because they do not like to be told what to do. Some patients are perceived as highly compliant but do not feel responsible for their health, do not build partnerships with HCP, do not ask questions, or sometimes do not follow the treatment or medical advice even if they do not express it openly. Finally, patients who are very rigorous might have a difficult time when treatment adaptability is suggested.

Patients also have to be ready and motivated (P3). Many HCPs stressed that patients need to be "ready" or in an "acceptance phase" to truly benefit from TPE because they will get involved and try to find solutions. The presence of distressing emotions such as anger or blocking coping strategies such as denial are considered to inhibit TPE benefits. Moreover, patients' other life events, concerns or priorities (e.g., relatives' health, work, financial

hardship etc.) should be considered. Professional conflict was reported as a source of distress that might prevent TPE efficacy. A patient might not be ready to become involved in TPE if highly distressing events are clouding their mind. Finally, patient motivation is consistently described as highly needed for TPE efficacy. Patients have to feel concerned, ready to take care of themselves, and have personal goals and motivation. TPE participation should be free and intentional to promote such personal motivation.

The social environment of the patient (P4) is also considered important. First, family members who are supportive can alleviate their sick loved one's distress with their good will. Moreover, when they are present for TPE sessions they can help the patient open up, see things differently, improve the relationship with the HCP and remember information the patient might forget because of stress. Close relatives may also take actions when needed to alert the HCP regarding their loved one's distress or problems. However, family members can also be a source of distress and guilt, notably if they are misinformed about their loved one's illness or hold prejudices. Thus, providing information for family members is important.

Regarding misinformation and beliefs (P5), patients do not enter TPE programs as a blank page. Fortunately, they have previous instructive experiences and useful knowledge. However, they might be misinformed about health matters, notably diet, through the mass media. Patients who are misinformed might spread harmful ideas during session groups. Moreover, patients might hold restraining representations (e.g., about psychologists or chemicals in medication) or unrealistic expectations (e.g., about medication or surgery outcomes). HCPs stress that they have to provide correct and scientific information without denigrating misinformed patients.

3.3. HCP characteristics thought to be associated with TPE efficacy

Through thematic content analysis or participant speech, four themes were derived regarding HCP characteristics affecting TPE (Table 4): (HCP1) medical up-to-date knowledge; (HCP2) appropriate attitude and relational skills; (HCP3) pedagogical skills; and (HCP4) training. Quotes are available in Table 4.

INSERT TABLE 4

First, HCPs should have robust, up-to-date and illness-specific medical knowledge (HCP1) to provide TPE effectively. Some HCPs stressed that this becomes increasingly important because of the mass media providing a lot of information and misinformation.

Moreover, HCPs should also have an appropriate attitude and relational skills (HCP2) to provide non-judgmental, non-directive, egalitarian interactions in TPE sessions. HCPs should not present themselves as "the one who knows everything" and give instructions. Of note, taking off the white coat is perceived as important to eliminate barriers between patients and the HCP.

Finally, HCPs should have pedagogical skills (HCP3). Those skills are various and include pedagogical aspects (Educational Diagnosis, setting objectives with the patient etc.) but also mastery of animation techniques (open questioning, allocation of speaking time, setting limits, manage group dynamics etc.). HCPs should also be able to structure the whole TPE program and use appropriate tools (establish the program sessions' format and goals, formalize documents and tools such as posters or card games etc.). Finally, evaluative skills are needed to assess both the patient and the TPE program itself (participation, satisfaction, knowledge, quality of life etc.).

As expected, training (HCP4) is considered essential to provide TPE. Training is mainly described as a way to develop skills mentioned above such as appropriate attitudes and relational skills (HCP2) and pedagogical skills (HCP3). Some HCPs complain about their lack of training, notably preventing them from gauging the quality of their TPE practices and improving them. Such lack of training might prevent feelings of competence and legitimacy. Training is sometimes provided by other HCPs in an informal manner. According to many HCPs, TPE must also be learned though experiential learning.

4. Discussion

The theme "patient's understanding and education" (P1) has been regularly highlighted in the literature and there is growing interest for health literacy and for its association with TPE efficacy ^{23,24}. Indeed, the impact of information and support provided by HCPs during TPE might be less significant if it is not understood and memorized, at least in part, by patients. Providing confusing information to patients might even be harmful because they might feel lost. HCPs can obtain a global impression of the patient's health literacy level, but precisely assessing health literacy requires validated tools, which could be used when assessing TPE efficacy ³⁹. TPE interventions should at least include universal precautions to reduce the complexity for all patients ²⁵ and consider tailoring content to specific patients' health literacy level ²⁴. Of note, we acknowledge that patients' understanding and education are not synonymous, but in HCPs' speech, both themes are often close to each other. Of note, some HCPs have highlighted that highly educated patients might require more detailed or scientific information to raise their interest.

In our results, patients' personality (P2) was considered a possible determinant of TPE efficacy. To our knowledge, no study has explored how patients' personality may affect TPE efficacy. Well-validated tools could be used to assess a patient's personality ⁴⁰ and to direct them to various TPE session formats. For instance, introverted patients might benefit from individual sessions or smaller groups with few speaking, whereas extroverted patients might benefit from larger groups involving role play. Similarly, patients who are compliant could benefit from information provided directly by HCPs. Less compliant patients could benefit from sessions

reinforcing therapeutic alliance and from recommendations mostly driven by their own experience or peer examples. Perhaps patients who lack curiosity might benefit from rewarding learning tools such as board games or even video games. These suggestions remain speculative, and further research should explore how patients' personality might affect TPE efficacy.

Patients' readiness and motivation (P3) can be linked to the transtheoretical model ^{41,42}. Patients in a precontemplative stage of change might not be motivated to take actions. Such patients could benefit from TPE sessions aiming at the process of change such as consciousness raising (finding and learning new facts, ideas, and tips that support the healthy behavior change), dramatic relief (experiencing the negative or positive emotions that go along with unhealthy behavior or new healthy behavior), or environmental reevaluation (realizing the negative impact of the unhealthy behavior or the positive impact of the healthy behavior on one's proximal social and/or physical environment) ^{41,42}. The Health Belief Model is in the same vein ^{41,43,44}. Patients who are not strongly motivated to take actions might benefit from strategies to improve perceived susceptibility to significant health problems, perceived benefits and barriers to healthy behaviors, and self-efficacy to perform such behaviors ^{41,43,44}. Moreover, for patients with a chronic disease, acceptance of the illness is an important determinant of TPE efficacy. HCPs are probably imbued with the model of grief ⁴⁵ which has been integrated in popular culture. HCPs mainly stressed that patients need to be free of strong and negative emotions that may prevent them to be receptive to TPE.

Patients' social environment (P4) is not sufficiently explored in the literature. Social support has been extensively described as a strong determinant of psychological health ⁴⁶ and also physical health ⁴⁷. It could be a source of encouragement and motivation to engage in healthy behavior directly or via better psychological health. Conversely, isolation could act as a barrier to health behavior adherence. Social isolation or lack of social support is routinely assessed during an Educational Diagnosis ⁴⁸. Patients who report such issues during an Educational Diagnosis could be directed to support groups, patient associations and communication technology facilitating contact with peers and HCPs. Indeed, social support group interventions have been found effective in improving various outcomes in people living with chronic illness ⁴⁹.

To our knowledge, few studies have taken into account the effect of a significant other attending TPE sessions directed to patients. Studies including parents might lead to more frequent significant results regarding TPE efficacy in adolescents and young adults ⁵⁰. Patients who are accompanied by loved ones during TPE sessions might benefit from more knowledge acquisition and real-life application. Participation with loved ones could also increase mutual understanding, empathy and trust. However, some studies of patients with rheumatoid arthritis

have reported that including a partner in TPE sessions might be ineffective or even increase fatigue and decrease self-efficacy ^{51,52}.

Finally, the theme misinformation and beliefs (P5) is interesting. Misinformation regarding health, notably via social media, is becoming an important public health issue ^{53,54}. Misinformed individuals are more likely to make poor health-related decisions such as refusing vaccines ⁵⁵, exhibit risky behaviors regarding HIV ⁵⁶ or inappropriate eating habits ⁵⁷. Thus, HCPs must provide scientific and up-to-date information to patients. However, they must keep a non-judgmental and respectful attitude toward misinformed patients. HCPs should consider addressing frequently reported misinformation (diet, vaccines etc.) and evaluate the efficacy of various tools to address it.

Of note, patients may also have unrealistic expectations regarding healthcare, medication or surgery. Expectations for positive outcomes after surgery has been found associated with better post-surgical quality of life ⁵⁸. However, overestimating benefits and underestimating harms is frequent in patients undergoing surgery or taking medication ⁵⁹. Unrealistic expectations have been found deleterious in patients undergoing bariatric surgery ⁶⁰ or knee and hip arthroplasty ⁶¹.

In our results, patients' cultural background and beliefs was mentioned rarely and only with reference to language barriers and dietary habits. Presumably, French HCPs might be reluctant to address ethnic issues. Such an attitude reflects a well-known national tendency to downplay the salience of cultural disparities in order to unify the nation ⁶². However, some studies suggest that patients from minority groups might benefit from culturally appropriate TPE interventions designed to match their values, practices and language and use educators from the same culture ^{26–28}.

Regarding HCP characteristics, in accordance with previous studies, HCPs should be up-to-date on their medical knowledge (HCP1) ^{31,32}. This seems especially important in terms of current misinformation about health issues spread via social media (P5) ^{53,54}. HCPs should also exhibit appropriate attitudes and relational skills (HCP2). This result mirrors the need for "high clinical experience" and the ability to be "empowering" reported in other studies ^{31,32}. These skills are essential to take into account patients' personality, understanding, motivation, social environment and beliefs to provide a non-judgmental intervention. HCPs should also exhibit pedagogical skills (HCP3). This result mirrors the need for updated knowledge about TPE and skills in teaching reported in other studies ^{31,32}. HCPs need to master Educational Diagnosis, one of the cornerstones of TPE ^{4,48}, and also animation techniques (open questioning, speech time allocation, setting limits etc.) to conduct TPE sessions. They should also be able to structure and assess their TPE program and sessions. Indeed, TPE is a structured approach

meeting internationally accepted quality criteria and must be defined in terms of activities, content, organization in time and educational tools, methods and evaluation ⁴. Finally, HCPs report that training in TPE is essential (HCP4). Training is a requirement of the French national health authority to conduct TPE programs ⁴. Training is mainly mentioned to increase the ability to structure and evaluate TPE programs (HCP3), but it might also increase and update medical knowledge (HCP1) and improve attitudes and relational skills (HCP2) and pedagogical skills (HCP3).

This study has some limitations. First, HCP checking of the results would have been an interesting way to insure more Credibility ⁶³. Moreover, our results are derived from French HCPs' speech. Patient and HCP characteristics that might affect TPE efficacy might be different in other countries because practices and values about health and healthcare are culture-dependent ⁶⁴. Further research could explore if such themes could be retrieved in other countries (Transferability ⁶³).

Nevertheless, this study has also some strengths. Participants were HCPs providing TPE programs for patients with various conditions and in various environments (hospital or not, rural or urban aeras). This maximation variation sampling ensure that a diverse sample of HCP was recruited, supporting Credibility and Authenticity ⁶³. Moreover, the coding process was the result of a triangulation including the perspectives of a health psychologist, a sociologist, and clinician/epidemiologist who provide different insights for a deeper and broader understanding of findings. This approach also support the Credibility and Authenticity of our analysis ⁶³. Finally, An inter-judge agreement between two coders was also computed, supporting the Confirmability of our results ⁶³.

In conclusion, various individual determinants might affect TPE efficacy: patient characteristics (understanding and education, personality, motivation and readiness, social environment and misinformation, beliefs and expectations) and HCP characteristics (knowledge, relational skills, pedagogical skills and training). Some of those determinants, such as understanding (health literacy), have raised scientific interest, but others remain understudied or underreported (patients' personality and expectations, HCPs' pedagogical skills etc.). Further studies should consider including assessments of such determinants to solve the "black box phenomenon" and to shed light on what might make a TPE intervention more effective than another 4,18. Various validated tools could be used to assess patient personality (NEO-PI 65), understanding (see Altin et al. 39), acceptance (Acceptance of Illness Scale 66), motivation (Situational Motivation Scale 67), life events (Revised Social Readjustment Rating Scale 68,69) and family relationships (see Pritchett et al. 70).

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Table 1 - Description of the sample of healthcare professionals.

Disease	Number of programs	HCP professions	Age class (years)	Experience in TPE (years)
	Dietician	21-30	< 1	
Cardiovascular diseases	2	Nurse	51-60	18
		Nurse	51-60	12
		Dietician	31-40	3
Kidney failure	2	Nurse	61-70	8
		Nurse	61-70	8
		Nurse	41-50	8
		Nurse	51-60	8
		Dietician	51-60	10
		Dietician	51-60	6
Rheumatic diseases	1	Nurse	51-60	12
COPD	1	Nurse	31-40	6
Asthma	1	Nurse	31-40	2.5
		Nurse	51-60	6
Chronic pain	1	Nurse	61-70	3
		Nurse	21-30	3
		Nurse	21-30	1
		Nurse	21-30	2
Multiple sclerosis	1	Nurse	51-60	10
Hepatitis	1	Nurse	31-40	6
Diabetes/obesity	1	Nurse	51-60	6
		Nurse	41-50	13
		Dietician	21-30	6
		Psychologist	51-60	10
Multiple pathology	1	Nurse	41-50	8
		Dietician	41-50	8
		Physiotherapist	41-50	8

Note. COPD: chronic obstructive pulmonary disease

Table 2. Content of the interview guide

Opening Questions. How do you practice TPE? What makes TPE successful or unsuccessful?

Organization and structure of the TPE program

Methods, facilitation, pedagogical tools used and customization

HCP-patient relationship

Role of the institution

Integration in the department/network, support

Role of training

Impact of patient characteristics

Impact of social factors

Integration of theoretical aspects in patient education

Other aspects not addressed during the time of interview

Note. HCP: Healthcare professional

Table 3. Examples of Healthcare Professionals' Verbatim About Patient Characteristics Thought to be Associated with TPE Efficacy

P1. Understanding and Education

- There are patients to whom we don't offer the program because there are really important cognitive deficits" (#9)
- "There are people with whom we're not going to go into so much detail because we're going to realize that they won't necessarily understand everything" (#14)
- "We realize the gaps, the intellectual barriers. I have patients who do not know that with four capsules of 1 mg and one of 0.5 mg, you have 4.5 mg. And we immediately understand that it's going to be difficult" (#9)
- "when we see that they don't understand, you can see it, so we help them, without denigrating them, because not everyone has the same intellectual level and that's not a reason to deny them the right to have support" (#9)
- "With people who don't understand French very well, who don't know how to write, we're really going to get to the basics." (#15)
- "We have people who are intellectually deprived so we try to use a vocabulary that is not the same for everyone and approach things in several ways, sometimes we say things 3 times in 3 different ways." (#16)

Highly educated patients

- "The more educated people are, the more they think they know everything and that TPE has nothing to offer." (#5)
- "When people are educated, they should be given scientific and 'rigorous' explanations." (#20)

P2. Personality

Introversion and extraversion

- "Some patients are very closed and do not express themselves because they are afraid of the judgment of others." (#9)
- "A rather withdrawn or expansive personality, sometimes very expansive, which can sometimes suffocate other patients in group sessions." (#2)

Curiosity and self-centeredness

• "Patients who tend to listen to themselves a lot, in general they are a little more focused on themselves, they talk about their difficulties but they do not really want to project themselves and expand their knowledge." (#21)

Impact of personality on compliance level

- "And then there is the one who will be very rigorous, even if I told him of course you can advance or postpone your injection by 24 hours, there is no problem. Ah no, no. With the patient profile it's difficult and it's up to me to adapt, but this very rigorous patient, it's absolutely not possible for me to tell him you can move forward or backward 24 hours because he won't be well." (#20)
- "There are people who are obedient. They obey, they do, they don't necessarily understand well why they do it but they do it because the doctor said so or the caregiver said so (...) They don't really own things so we're not really in a partnership. They think what they want but they are compliant because the doctor said...." (#28)
- There are those who in consultation will say yes and when you open their medicine cabinet, all the boxes that have been prescribed for 2 years fall down." (#28)
- "Some patients are a little rebellious and don't want to... There are people who have a profile, how can I say this, they don't like to be told things, that's how it is." (#4)

P3. Being Ready and Motivated

Acceptance phase

- "Joining the program, it's already accepting the journey and it indicates a useful state of mind to be able to move on." (#9)
- "In order for TPE to work, the patient must be in the acceptance phase of one's own disease." (#17)
- "If [the patient] has accepted the disease, we are very pleased because [they] will get involved and will try to find solutions." (#28)

Appropriate time of one's life

- "We ask them what is the most serious thing in their lives. When someone comes in with kidney failure but tells us 'go back to work' or 'I have a grandson who is very sick, I worry about him' or 'I have a lot of debts, I don't know if I will still have a home tomorrow morning.' These people, we have to help them find their way and maybe it's not the right time to talk to them about their illness." (#10)
- "When there are other things that interfere such as social, psycho-social, environmental, problems. All that, if it is not taken into account, it doesn't work We'll be able to educate [them] better if [they are] free in their head." (#10)
- "I've had a lot of patients like that who have had a work accident, who have been disabled with chronic pain that really prevents them from living. These patients are in lawsuits with their bosses. We realize from all these similar stories that we have, we have a lot of them here, that we're only going to start doing really good work on pain when this problem, which is a problem of injustice for them, is resolved." (#16)

Intrinsic motivation and readiness to self-help

- "The patient has to be motivated and to have goals such as working out." (#15)
- It's important that patients come to the TPE sessions for which they really feel concerned because it makes them more involved." (#23)
- "A patient who wants to come to TPE, who isn't present because [they are] forced to come once a month because the doctor says 'if you don't go we won't start the treatment'.

 It can actually be a hindrance." (#21)
- "Patients who mainly expect to get answers from us don't necessarily plan to take care of themselves." (#18)
- "Patients who have been waiting for years don't believe in it anymore." (#18)

P4. Social Environment

Family support

• "If family members are supportive and helpful, even if they don't necessarily understand what's happening to their loved one, because of their goodwill, it will also help us to make the patient less suffering or the family less suffering because sometimes they're both suffering" (#17)

- "People who come with someone in consultation will also confide in us more easily." (#21)
- "I think that's a plus, because they often have a very negative state of mind ... Recently a girl said 'Since you are taking your treatment you don't realize, you look better. I find you much more in shape.' It allows them to have another perspective and to work on the feeling they may have." (#21)
- "The really important information is heard by two people. The patient often hears half of the information. The other half, it's forgotten because the patient is a bit stressed out.

 When there are two people coming to a consultation, there are two persons listening and they rarely hear the same things." (#21)
- "Sometimes I even had the family calling me to tell me there's a problem, [the patient is] not doing well, [the patient] doesn't dare to call you, so sometimes they really take actions, they're really actors." (#21)

Deleterious family

- "We have a lot of drug addicts, many of them are 40 or 50 years old, former drug addicts, who don't have a job, who often live with their parents. Their parents are now old, 80 years old, and for them hepatitis is a shameful disease, clearly with many false beliefs, unfortunately ... These patients are going to be a little more particular than others. Because they are ... wanting to get rid of their disease but they are not too supported by their entourage. On the contrary, their entourage has rather a guilt impact on them." (#21)
- "There are people in the entourage of people with chronic pain who have no idea what chronic pain is. So, if we can also bring them some knowledge, perhaps they will understand more about their husbands, wives, etc." (#18)

P5. Misinformation and Beliefs

Misinformation

• "We correct misconceptions too, the beliefs they have about certain foods." (#5)

- "Some patients because of their beliefs, their convictions, by the readings, are convinced that you have to stop eating dairy products when you have cancer. When you find yourself facing a patient who has this idea and who can propagate it in a group, it can be a bit harmful We have to present scientific arguments to show that it's not the case."

 (#2)
- "They are imbued by the Internet and they have a lot of preconceived ideas, well, what we call preconceived ideas but which for them are truths." (#12)
- "Because often 'heart' for them means 'I don't have the right to do anything anymore'." (#4)
- "There are patients who refuse treatment, even after the TPE, even after many meetings with the neurologist, who refuse the treatment, because in their belief or in their way of managing their body, it is a product that may be toxic for them, so they will turn to alternative medicine such as herbal medicine. My role is not to make them feel guilty but to make them realize that the scientific data show that we have better outcomes with treatments." (#20)

Representations and unrealistic expectations

- "A lot of people say 'oh no, I don't want to see a shrink' and finally after 3 or 4 TPE sessions, I have [shown] them another picture and they were ready to go and see a shrink."

 (#25)
- "They think that because they enter in an anti-pain unit they won't have pain during all their stay and will leave cured. But we have to explain them that they're going to be in pain even here because it's not magical and when they'll come out they'll still be in pain. We have to explain that it's more nuanced, that they'll have less pain, but you have to tell them right away and that's often a shock." (#17)

Table 4. Examples of HCP Verbatim About HCP Characteristics Thought to be Associated with TPE Efficacy

HCP1. Medical up-do-date knowledge

- "You have to know the disease well to be right on course." (#17)
- "You have to know the current events for this pathology and what can be offered to patients." (#26)
- "Today mass media circulate a lot of information and patients come with their request and they come with their request also to the doctor so we need to be able to either give them their information if we know it immediately or answer in a quick time to their questions." (#26)
- "When I've heard over the last few years, that anyone can do TPE with any disease. Well, no. You have to know." (#20)

HCP2. Appropriate Attitude and Relational Skills

- "We are in civilian clothes so it's no longer the same relationship and patients perceive us more as a help, we will formulate questions, but we won't judge their answers. They won't have to do it right. We will help them understand what is happening to them, so we are no longer seen in the same way." (#9)
- "The absence of a white coat makes it possible to remove the 'white coat effect'; it brings back a more human side without the medical side." (#8)
- "Offering physical exercise in [a] sports outfit is an effort for these people; I feel it, getting involved in the group and bringing me up to their level, the exchange is much easier, I have much more information and people come to tell me 'Well, I have to show you'. I don't have this role of observer, of judge for them that would be very badly perceived."

 (#22)
- "But also, the gestures not to be surprised, if the patient tells you something and that's sometimes it's not always easy to have an open posture." (#11)

HCP3. Pedagogical Skills

Educational diagnosis

- "Above all, the educational diagnosis which is the first stage of TPE, for me, it was still vague until I had the training I didn't necessarily tackle all the dimensions that the educational diagnosis represents. "(#1)
- "Take the time to explain to them what we were going to do and the objectives that we set ourselves and to ask for their agreement." (#28)

Animation technique

- "To make the speech rotate for all patients." (#11)
- "Talking to the patient with open questions, not yes-no questions, that doesn't lead to anything." (#9)
- "Not only giving information, having a dialogue, it is especially that, which we learned." (#11)
- "How far you can let people talk, because you have to set a limit, otherwise they talk about the professional, they talk about the diagnosis you have to try to frame them and that can be learned." (#19)
- "You also have to know what to say when you hear things you can't hear, what you have to rephrase. When you say that the person wants to commit suicide, it's a bit complicated; it puts a weird shock in the room; how do you bounce back? It's group dynamics." (#19)
- "To be able to have the same speech in front of the patient, because we all had personal feelings and we conducted our interviews through our own experience, without necessarily having the pedagogical techniques to do so." (#9)

TPE program structure and tools

- "To better structure things and to come out of it with an established program, by following specifications." (#12)
- "I had the feeling that I formalize better what TPE is. All that was new was the formalization of the documents to be completed, the way to make an TPE program, to define the content of the workshops ... not just distributing documents because that is information." (#5)

• "We have correct tools with nice posters, card games to play with the patients to learn the foods; it was prettier and a little more uniform." (#4)

Patients' evaluation skills

- "Knowing how to evaluate an objective in a patient, know whether it needs to be improved." (#18)
- "Evaluation sheets with grids." (#1)

TPE program evaluation skills

- "Knowing how to evaluate the things we do here and whether we do it well." (#18)
- "That there were things that needed to be looked at in more depth, such as quality of life assessment with a questionnaire that I have put in place. And then because it was formalized over a year, the follow-up is better. Before formalizing this program, before the program was accepted in 2012, I followed the patients; I called them. But it was less formalized, I didn't have a board, I didn't have it, it was less rigorous, it was the patient who called me if [they] needed it." (#21)

HCP4. Training

Skill development

- "Training allowed me to approach care and education really differently. If I want to caricature a little bit, it's not the teacher who gives her class and 'it's like that' and 'you have to', whereas now we realize that it's not like that at all, we use the potential of people we didn't use at all before." (#22)
- "Training allowed me to better structure things and come out with an established program, following a set of specifications." (#12)

Lack of training and feeling of inadequacy

• "We were never told too much about how to do it. We're not really trained in all this. So how can we judge whether it's to be improved or acquired, knowing that we do not have the necessary knowledge to assess whether it is to be improved or acquired?" (#18)

- "What we do is obvious because it's what we've always done. We see that it necessarily adds, but we think to ourselves Is it not too much? Is it well done? Is it not too fast to come to terms with the patient's emotions? Is it the right way? I wouldn't say that I want to have a complete training since it's the practice that gave it to us as well, but maybe there are some techniques I'd like to learn to see if we have the right approach." (#18)
- "No, I'm not trained, and I've been here for 6 years and I've never been trained in TPE. I do TPE but are we doing it right? That's the whole question. We were thrown into it by saying 'We have to do TPE.' An old person who used to manage it trained us a little bit by explaining the purpose, how to start the session, what can be expected from it, etc. We passed the word a little to each other, how to start from the beginning, how you end I'm not trained either and nobody is trained in group dynamics but here we are, we learn from the pile of little mistakes." (#19)