

French Recommendations for a National Competency Framework of Therapeutic Patient Education in Solid Organ Transplantation

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THERAPEUTIC EDUCATION AND PATIENT CARE PATHWAY: THE FRENCH EXPERIENCE

Therapeutic patient education (TPE) is a patient-centered process, fully integrated in health care, aiming to help patients with chronic disease advancing means of self-care, independence, and adaptation competencies, to maintain

or improve their quality of life.¹ Uniquely positioned, the French law has rendered TPE as a requirement of patient care since 2009.² The biomedical model has focused on pathologies and treatments, in a disease management mode targeting mainly the improvement of compliance.^{1,3} A humanistic biopsychosocial model has recently emerged in France, leading to education approaches centered on the development of psychosocial and adaptation competencies.

In this context, a generalist national competency framework for healthcare professionals, helping teams to integrate both biomedical and psychosocial approaches in their TPE programs, has been published by the French health authorities.

THE CHALLENGE OF THERAPEUTIC PATIENT EDUCATION IN SOLID ORGAN TRANSPLANTATION

By improving transplant patients' autonomy, TPE aims to optimize successful outcomes, including improved quality of life, better coping with side effects or decreased risk of graft loss.³⁻⁷ In this scientific and regulatory context, French transplantation centers should offer a TPE program to all patients.

Approximately 5000 organ transplantations are currently performed at 58 centers in France, coordinated by the French Biomedicine Agency. Notably, centers have been challenged by limited funding resources, and geographic disparities have become obvious. In 2018, only 46 centers in 12 regions have been able to offer a program based on diverse competency frameworks established in each of the participating centers that communicate comparable competency and learning objectives.

KEY SKILLS FOR SOLID ORGAN TRANSPLANT PATIENTS: THE ADVANTAGES OF A UNIVERSAL COMPETENCY FRAMEWORK

TPE cannot be standardized among centers as the concept depends on local specificities and means. Thus, a unique reference competency framework rather than a standardized program may help harmonize existing while establishing new programs. Importantly, a nationally validated competency framework may contribute to upgrading the quality of practices. Although the majority of transplant teams in France are involved in TPE, healthcare professionals

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need training, and the reference competency framework may help to disseminate a common approach. In addition, evaluating the success of TPE is challenging, as a beneficial impact on both biomedical and psychosocial outcomes is expected. A common reference competency framework is expected to support evaluating the benefits of TPE in everyday practice and during clinical trials. Moreover, and in addition to the French experience, a harmonized competency framework may represent a new and useful tool for the international transplant community, harmonizing objectives when conducting international trials and comparing results in different settings. With that rationale, the French-Speaking Transplantation Society (Société Francophone de Transplantation) suggested a national competency framework in solid organ transplantation.

A NATIONAL COMPETENCY FRAMEWORK IN SOLID ORGAN TRANSPLANTATION: THE METIS PROJECT

The METIS project, conducted between 2019 and 2021, aimed to elaborate a national competency framework in solid organ transplantation based on the Delphi method.⁸ A pilot group of 11 experts in the fields of transplantation, TPE, public health, and clinical research was charged to delineate the project and moderate each successive round of the process. An expert panel consisting

of 54 physicians, 7 surgeons, 27 nurses, 13 pharmacists, 4 dieticians, 3 sports instructors and physiotherapists, 7 psychologists, and 14 patients originating from 37 adult and pediatric transplantation throughout the country was established. Participating patients had received kidney (n = 8), liver (4), kidney and liver (1), and heart transplants (1). Experts were asked to express their level of agreement about including various propositions into the national competency framework. The same list served as the main thread throughout the process, refined at each round of discussions. Propositions that had received a strong immediate or a relative consensus during 2 sequential rounds were included in the final competency framework.

A unique competency framework with relevance to all adult and pediatric recipients of solid organ transplants was considered most relevant by the pilot group. A first series of 76 propositions arose from a brainstorming session based on existing competency frameworks. Consensus was achieved after 3 rounds and 78 experts participated throughout the entire project. The Delphi process led to discarding 2 and adding 8 propositions, generating a framework including 82 adaptation, self-care, and safety competencies, categorized into 6 themes (knowledge about transplantation, experience of transplantation, treatment management, hygienic and dietary measures, monitoring and alerts, daily life) (Table 1). In addition to classical biomedical objectives such as managing treatment or adopting

TABLE 1. List of Skills Proposed During the METIS Consensus Conference for the Elaboration of a Skills Repository for Therapeutic Patient Education in Adult and Pediatric Solid Organ Transplantation

Skill no.			Results by round				Decision
			R1	R2	R3		
R1	R3	Proposals					
Knowledge about transplantation							
Self-care skills							
1	1	Knowing and understanding that transplantation is one of the treatments of organ insufficiency	A+	A+		Accepted	
2	2	Understanding the principles of the surgical procedure of transplantation	A?	A+		Accepted	
	3	<i>Understanding the risks of the surgical procedure of transplantation^a</i>	New item	A+	A+	Accepted	
3	4	Being able to locate the graft	A+	A+		Accepted	
4	5	Understanding rejection and being able to explain it	A+	A+		Accepted	
5	6	Knowing that the graft <i>may^a</i> have a limited survival over time	A+	A+		Accepted	
Adaptation skills							
Self-knowing							
6	7	Being able to explain transplantation to relatives (family, friends, colleagues)	A+	A+		Accepted	
7	8	Understanding whom the graft comes from (deceased donor, living donor)	A+	A+		Accepted	
Experience of transplantation							
Adaptation skills							
Being self-confident							
8	9	<i>Expressing his/her feelings^a</i> on organ donation (deceased donor, living donor)	A+	A+		Accepted	
9	10	<i>Accepting the fact of being transplanted^a</i>	A+	A+		Accepted	
10	11	Accepting his/her new image	A+	A+		Accepted	
11	12	Being able to talk about his/her transplantation with others	A+	A+		Accepted	
12	13	Being able to talk about his/her transplantation with his/her donor (in case of a living donor)	A+	A+		Accepted	
	14	<i>Being able to inform his/her relatives that they can benefit from therapeutic education sessions^a</i>	New item	A+	A+	Accepted	
Adaptation skills							
Dealing with emotions and stress							
13	15	Being able to express his/her difficulties to his/her relatives	A+	A+		Accepted	

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TABLE 1. (Continued)

Skill no.			Results by round			
R1	R3	Proposals	R1	R2	R3	Decision
14	16	Being able to express his/her difficulties to the healthcare team	A+	A+		Accepted
	17	<i>Being able to identify resource persons (close relatives, hospital and outpatient healthcare professionals)^a</i>	<i>New item</i>	A+	A++	Accepted
15	18	Knowing the names of <i>patients associations which can be solicited when necessary^a</i>	A+	A+		Accepted
16	19	Being able to express his/her fear of rejection and finding the resources when necessary	A+	A+		Accepted
17	20	Accepting that graft survival over time is limited	A+	A+		Accepted
18	21	<i>Becoming aware of^d the possible complications of transplantation</i>	A+	A+		Accepted
19	22	<i>Becoming aware of^d the impact of transplantation on daily life</i>	A+	A+		Accepted
Treatment management						
Self-care and adaptation skills						
Understanding and managing the treatment						
20	23	Knowing his/her immunosuppressive treatment	A+	A+		Accepted
21	24	Understanding his/her immunosuppressive treatment (antirejection and side effects)	A+	A++		Accepted
22	25	Understanding what his/her medications are used for	A+	A+		Accepted
23	26	Organizing his/her drug intake (ex: pill organizers)	A+	A+		Accepted
24	27	Managing his/her medication stock/avoiding stock shortage	A+	A+		Accepted
25	28	Knowing how to store his/her medications in appropriate conditions	A+	A+		Accepted
Adaptation skills						
Setting objectives						
26	29	Choosing, together with the healthcare team, the modalities of drug intake adapted to his/her daily life and taking into account the constraints related to the drugs (hours of intake)	A+	A+		Accepted
Adaptation skills						
Solving problems or particular situations						
27	30	Managing his/her immunosuppressive treatment in case of a missed dose	A+	A+		Accepted
28	31	Managing his/her immunosuppressive treatment in case of vomiting	A+	A+		Accepted
29	32	Knowing how to react when a generic is proposed in an outpatient pharmacy office	A+	A+		Accepted
30	33	Adapting drug intake when he/she goes for a meal with a group or at a restaurant	A+	A+		Accepted
Hygiene and dietary measures						
Adaptation skills						
Setting objectives						
31	34	Adjusting his/her nutritional objectives (proteins, carbohydrates)	A+	A+		Accepted
32	35	<i>Controlling his/her^a weight</i>	A+	A+		Accepted
33	36	Adjusting his/her sodium and water intake	A+	A+		Accepted
34	37	Knowing the effects of alcohol on his/her transplant and health	A+	A+		Accepted
	38	<i>Considering weaning or discontinuing alcohol consumption^a</i>	<i>New item</i>	A+	A+	Accepted
	39	<i>Knowing the effects of drugs on his/her transplant and health^a</i>	<i>New item</i>	A+	A++	Accepted
35	40	Adopting some physical activity adapted to his/her health status	A+	A+		Accepted
36	41	Knowing the food <i>and situations^a</i> generating a risk of infection	A+	A++		Accepted
37	42	Knowing the food interacting with immunosuppressive drugs	A+	A+		Accepted
	43	<i>Knowing the effects of tobacco on his/her transplant and health^a</i>	<i>New item</i>	A+	A++	Accepted
38	44	<i>Considering weaning or quitting tobacco^a</i>	A+	A+		Accepted
Monitoring and alerts						
Self-care skills						
Being proactive						
39	45	Knowing and understanding the modalities of his/her short- and long-term follow-up	A+	A++		Accepted
40	46	Knowing and understanding the objective and modalities of performing biopsies	A+	A+		Accepted
	47	Knowing and understanding the objective and modalities of complementary analyses	<i>New item</i>	A+	A++	Accepted
41	48	Knowing and understanding the objective and modalities of therapeutic drug monitoring	A+	A+		Accepted
42	49	Knowing and understanding the objective and modalities of dermatologic follow-up	A+	A+		Accepted

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TABLE 1. (Continued)

Skill no.			Results by round			
R1	R3	Proposals	R1	R2	R3	Decision
Self-care skills						
Mastering self-monitoring procedures						
43	50	Knowing to weigh him-/herself	A+	A+		Accepted
44	51	Knowing to check his/her temperature	A+	A+		Accepted
45	52	Knowing how to use the blood pressure monitor and, if possible, reading and copying his/her blood pressure	A+	A+		Accepted
46	53	Knowing how to monitor or have a physician monitor his/her skin	A+	A++		Accepted
47	54	Knowing how to monitoring his/her FEV1	U?	U?		Rejected
48	55	Knowing how to monitor his/her capillary glycemia, depending on the pathology	A+	A+		Accepted
Safety skills						
Identifying crisis situations and acting accordingly						
49	56	Knowing his/her weight objective and alerting if necessary	A+	A+		Accepted
50	57	Knowing how to identify fever and alerting if necessary	A+	A++		Accepted
51	58	Knowing his/her blood pressure objectives and alerting if necessary	A+	A+		Accepted
52	59	Knowing to detect a suspicious cutaneous lesion or a modified nevus and alerting if necessary	A+	A+		Accepted
53	60	Knowing his/her blood FEV1 objectives and alerting if necessary	A?	A?		Rejected
54	61	Knowing his/her blood glycemia objectives and alerting if necessary	A+	A+		Accepted
55	62	Knowing to read <i>the biologic results important for his/her transplantation^a</i> and alerting if necessary	A+	A+		Accepted
56	63	Knowing his/her immunosuppressive drug concentration target and alerting if necessary	A+	A+		Accepted
57	64	Identifying the signs evocative of graft dysfunction	A+	A+		Accepted
58	65	Adopting appropriate actions in case of alert clinical signs (fever, vomiting, diarrhea, cough, dyspnea, urinary burning, edema, jaundice)	A+	A++		Accepted
59	66	Understanding the importance of treating complications rapidly	A+	A+		Accepted
60	67	Knowing to seek transplant healthcare professionals in case of alert clinical signs	A+	A+		Accepted
Adaptation skills						
Solving problems or particular situations						
61	68	Knowing to explain his/her health status to healthcare professionals other than the transplant team	A+	A+		Accepted
62	69	Daring warn and alert on drug interactions risks in case of a new prescription	A+	A+		Accepted
63	70	Identifying possible side effects of drugs	A+	A+		Accepted
Daily life						
Self-care skills						
Asserting rights						
64	71	Asserting his/her social rights	A+	A+		Accepted
Adaptation skills						
Undersanding and managing his/her treatment						
65	72	Hedging against the risk of infection and having his/her vaccinations up-to-date	A+	A++		Accepted
66	73	Knowing the risks of self-medication	A+	A++		Accepted
67	74	Knowing the limits and risks and limits of phytotherapy and alternative medicine	A+	A+		Accepted
68	75	Understanding the importance of contraception <i>and being informed of the risks of beginning a pregnancy while on immunosuppressive drugs^a</i>	A+	A++		Accepted
Adaptation skills						
Solving problems or particular situations						
69	76	Advising the transplant team of a parental project and preparing a pregnancy	A+	A++		Accepted
70	77	Organizing his/her meals and treatment in particular situations (family, friends and professional meetings, going out for meals)	A+	A+		Accepted
71	78	Protecting him/herself from the risk of infection when his/her relatives are sick or in case of a sanitary crisis	A+	A++		Accepted
72	79	Protecting his/her skin	A+	A++		Accepted
73	80	Preparing a travel: informing the transplant team, organizing his/her treatment (stock, conservation, transportation), organizing drug intake (journey, time difference), health insurance, vaccination	A+	A+		Accepted
74	81	Daring ask for help in case of social or economic problems	A+	A+		Accepted
75	82	Daring ask for help in case of school problems	A+	A+		Accepted
76	83	Daring ask for help in case of psychological problems <i>or bad experience of the transplantation^a</i>	A+	A+		Accepted
	84	<i>Being able, if necessary, to communicate on his/her affective or sexual life</i>	New item	A+	A++	Accepted

Bold highlights skills considered appropriate, with a strong agreement between experts.

^aItalics highlights skills added or reworded between round 1 and round 2.

?, uncertain agreement; +, relative agreement between experts; ++, strong agreement between experts; A, appropriate; R, round; U, uncertain.

appropriate hygiene and dietary measures, the framework includes a variety of psychosocial skills. Asking for help in case of psychological suffering, socioprofessional or school difficulties, organizing social activities, or having a parent-hood project are examples of major emotional, psychosocial, and socioprofessional matters that have been included in the competency framework.

IMPLEMENTATION OF THE NATIONAL COMPETENCY FRAMEWORK

This METIS project implemented a unique, national competency framework for TPE in transplant patients and will be disseminated for implementation in all French transplantation centers. The framework includes a wide variety of self-care, safety, and adaptation skills related to transplantation, treatment, and follow-up modalities. By addressing psychosocial and emotional issues, the framework will help healthcare teams to support patients in managing their life after transplantation, thus contributing to improved outcomes. TPE should be based on a holistic approach and be offered during early and late stages posttransplantation.⁹ Therefore, timing relative to transplantation will have to be defined for each skill, and the competency framework will be combined with a user guide facilitating its effective utilization. As a next step, the framework will be submitted to the French Health Authorities and Agencies to assist in its implementation.

CONCLUSION

We present the first national competency framework for TPE. This framework, established by a group of experts representing patient and providers, is of significant relevance in solid organ transplantation, as it is expected to (i) aid transplantation teams in constructing new or implementing existing programs; (ii) contribute to harmonizing TPE programs and learning objectives; (iii) contribute to upgrading the quality of patient care; and (iv) help conduct multicenter clinical trials on TPE.

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