



Patient Experience in Pancreas-Kidney Transplantation—A Methodological Approach Towards Innovation in an Established Program

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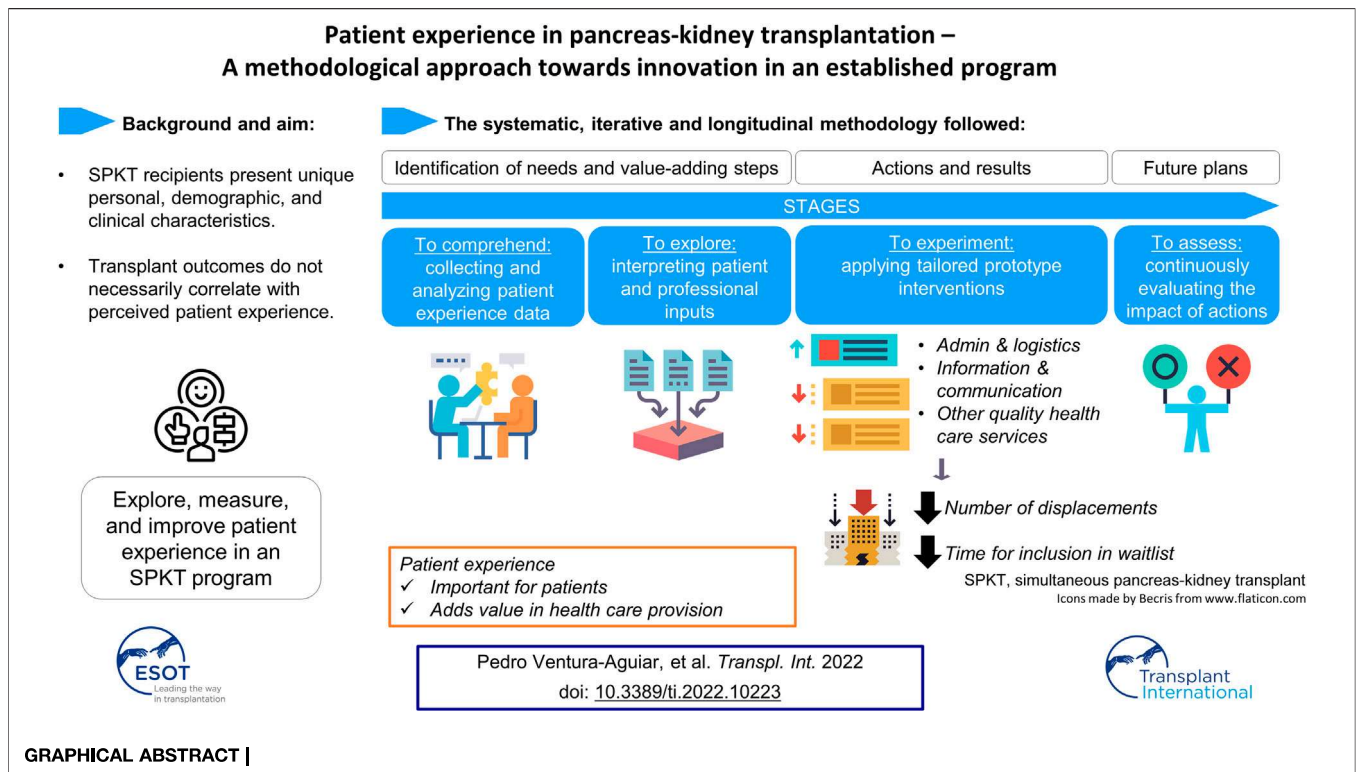
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Simultaneous pancreas-kidney transplantation (SPKT) leads to increased survival and quality of life, and is an alternative treatment for insulin-dependent diabetes mellitus and end-stage kidney disease. Due to the particularities of this population (often with multiple comorbidities) and of the surgery (only performed in a few centers), a comprehensive analysis of patients' experience along the SPKT process is crucial to improve patient care and add value to this procedure. Therefore, we applied a systematic and iterative methodology with the participation of both patients and professional teams working together to explore and identify unmet needs and value-adding steps along the transplant patient journey at an established pancreas transplant program. Four main steps (to comprehend, to explore, to experiment and to assess) led to several interventions around three major areas: Administration and logistics, information and communication, and perceived quality of assistance. As a result, both displacements to the hospital for diagnostic purposes and the time delay involved in joining the patient waiting list for transplantation were reduced in parallel to the administrative procedures. In conclusion, the methodological implementation of key organizational changes has great impact on overall patient experience. Further quantitative analysis from the patient's perspective will consolidate our program and may add new prototype service design components.

Keywords: diabetes mellitus, simultaneous pancreas-kidney transplantation, chronic kidney failure, patient care, organizational innovation, focus groups

Abbreviations: A&E, Accident and Emergency; ANE, Anesthesiology; AQuAS, Catalan Agency for Health Quality and Evaluation; BMI, Body Mass Index; DALYs, disability-adjusted life years; DM, diabetes mellitus; ESRD, end-stage renal disease; HBP, Hepatobiliarypancreatic surgery; HCB, Hospital Clinic Barcelona; NEF, Nephrology; ONCE, Spanish National Organization for the Blind; PREM, patient-reported experience measures; PROMs, patient-reported outcome measures; SPKT, simultaneous pancreas-kidney transplant; QoL, quality of life; T1DM, Type 1 diabetes mellitus; T2DM, Type 2 diabetes mellitus; URO, Urology.



INTRODUCTION

In Type 1 diabetes mellitus (T1DM), the immune destruction of pancreatic beta cells leads to deficient production of insulin and renders patients dependent on life-long exogenous insulin therapy. Approximately 50% of diabetic patients develop serious complications, including chronic kidney disease (1), which was responsible for approximately 82,000 deaths worldwide and 3 million disability-adjusted life years (DALYs) in 2019 (2). Diabetic nephropathy is the leading cause of end-stage renal disease (ESRD) (3, 4). In these cases, simultaneous pancreas and kidney transplant (SPKT) is preferred over kidney transplant alone as it leads to increased patient and kidney graft survival rates (5–7). Moreover, since SPKT restores both organ functions in a single procedure, it overcomes the need for dialysis, insulin therapy, dietary restrictions and, most importantly, it minimizes diabetic complications (8, 9).

Concomitant improvement in quality of life (QoL) and other patient-reported outcome measures (PROMs) have also been extensively reported in cross-sectional studies including SPKT patients (10–14). However, none included patient reported experience measures (PREMs) throughout the transplant process. In this regard, several authors agree that prioritizing what patients value is key in quality healthcare provision. In the last years, patient's appraisal of their own experience with healthcare services has received much attention, with an ever-increasing number of studies that consider it in the design and upgrade of health systems (15–18). The major challenge lies in translating the heterogeneity of individual patient experience into measurable categories. For this, identifying the stakeholders

involved in patient care and defining the patient journey map are useful to sort and characterize the added-value and non-added-value steps in the healthcare process (19). Qualitative data can subsequently be collected by methods such as interviews with patients, surveys and focus groups (19–22).

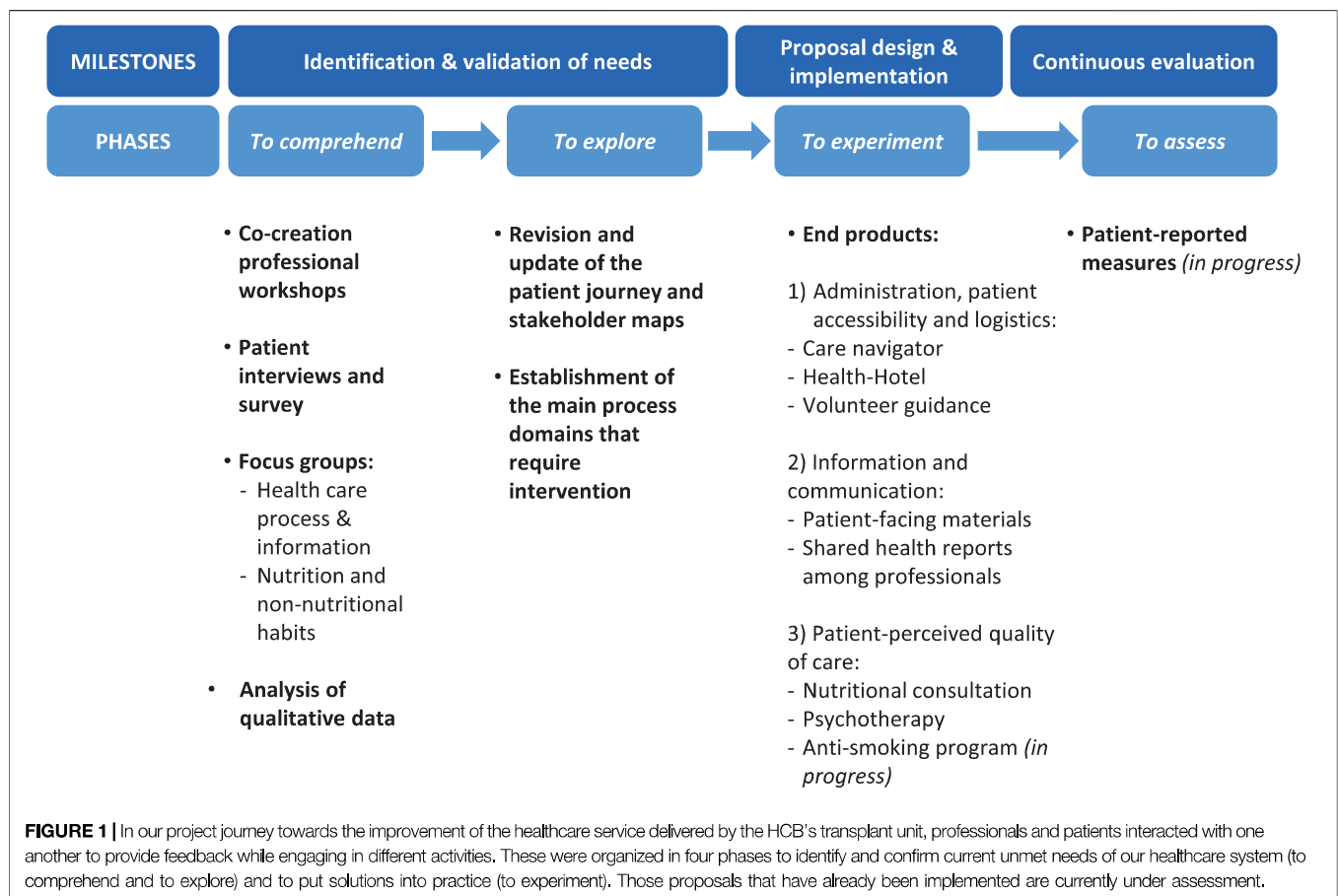
Herein we present a study aimed at integrating patient experience into qualitative healthcare assessment within the Pancreas-Kidney Transplant Program at the Hospital Clinic Barcelona (HCB). In order to achieve this, we followed a systematic, iterative and longitudinal research methodology to acquire data from patients and professionals while they interacted with each other.

PATIENTS AND METHODS

Study Design

We designed a systematic methodology to assess patient experience and improve the quality of the well-established Pancreas-Kidney Transplant Program at the HCB. This patient-centered project was developed in four phases that aimed to identify and validate current unmet needs and/or value-adding steps in our transplant process of care, as well as implementing specifically designed prototype proposals (**Figure 1**):

- 1) To comprehend—to collect and analyze data regarding the status of patient experience at the HCB (Pancreas-Kidney Transplant Program) from both professional and patient sources. Specifically, a team of professionals revised the relevant literature and were brought together at five co-



- creation workshops. The activities involved mixed patient-professional teams taking part in three focus groups, a patient interview, an online survey and several open informative events for patients on social media (23–26).
- 2) To explore—to dissect and interpret the newly acquired information on uncovered or upgradable healthcare domains while checking to what extent they can be generalized.
 - 3) To experiment—to design and implement new proposals according to the unveiled unmet needs.
 - 4) To assess—to continuously evaluate the impact of the novel processes applying PREMs (currently in progress).

All these steps were carried out at the HCB, Spain, between October 2020 and February 2021. HCB performs an average of 20 pancreas transplants per year and is the main referral hospital for patients from five Spanish autonomous regions as well as Andorra (27, 28).

Study Participants

Healthcare Professionals

In 2019, the HCB established the Patient Experience Team, which is a living lab and multidisciplinary group of professionals (a sociologist, psychologist and physician) who work on the evaluation of the patient experience and on the design and analysis of PREMs following implementation of new protocols (29–31).

For this study, a total of 13 healthcare professionals from different disciplines and educational backgrounds were involved, including members from the HCB Patient Experience Team and others (physicians, nurses, administrative staff, a nutritionist and a participatory health care consultant). Professionals were involved in all co-creation workshops and focus groups.

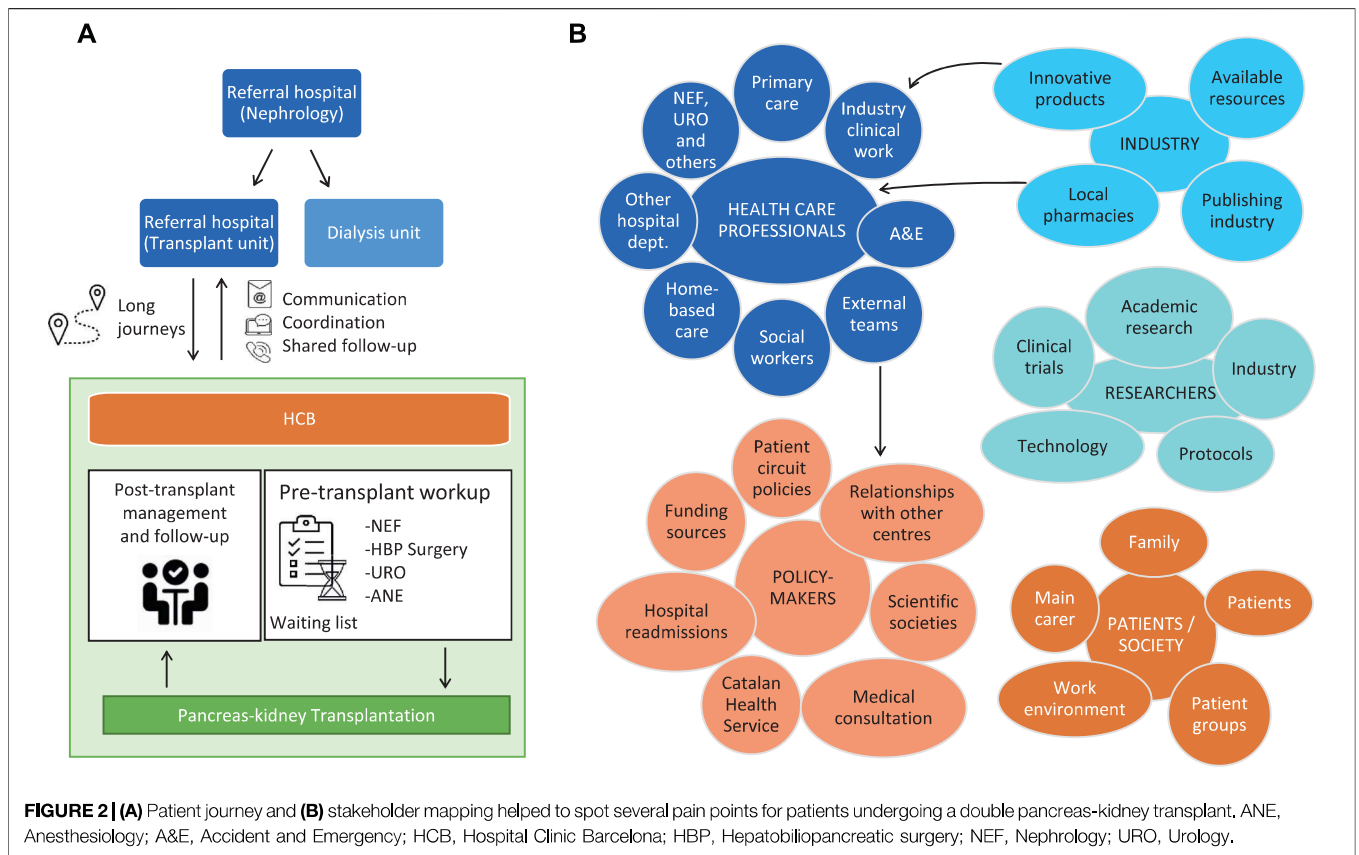
Patients

A total of 12 patients worked together with the multidisciplinary professional team. Five patients participated in the focus group sessions, five responded to a logistics survey by email and two were interviewed online on World Diabetes Day 2020 (23). Patient selection was made according to clinical and demographic data and aimed to represent all patient archetypes that had been defined during the previous co-creation workshops.

Data Collection and Analysis

Focus Groups

Focus groups were carried out virtually and lasted between 60 and 90 min. Prior to the sessions, the focus group agenda was agreed on by the multidisciplinary professional team. Following contact, patients willing to participate received detailed information regarding the objective of the session, connection instructions as well as the consent form to participate and be recorded. Focus group sessions were moderated by two members from the patient



experience team. Of relevance, principal care physicians did not participate in these sessions, to avoid biasing patients’ responses and interaction. In each session, the moderators introduced the purpose and aims of the study. Participants were also reminded that they would be recorded, and that all data collected during the session would be treated anonymously and confidentially. At the end of the session, patients were asked an open-end question in order to gather further feedback and/or suggestions.

During the first focus group, patients validated the general areas of improvement identified during the previous process mapping (Table 1; Figure 2), patient interview and survey (Supplementary Tables S1, S2). Afterwards, a formal script was prepared (Supplementary Table S3) for the second and main focus group about the healthcare process & information. Here, patients helped to identify the specific domains that needed to be addressed in the transplant unit and discussed them extensively (Table 2). The session was also useful for gaining aware of the emotions that were generated in each step of the care process (Figure 2).

MAXQDA software (VERBI GmbH, Germany) (32) was used to analyze the data from the verbatim transcriptions of the recorded focus group sessions. The analyses gave rise to the coding of meaning units (all expressions that have the same meaning) which were then combined into meta-categories. Further qualitative analyses (absolute frequency of meaning units) were performed according to the COREQ criteria for qualitative research (33, 34).

Patient Data

Patient data regarding the variables study time and number of displacements were collected from patients’ electronic registries from 2019 to June 2021. Study time was defined as the total time since the first evaluation for pancreas transplantation until clinical decision regarding inclusion/exclusion of the patient in/from the waiting list. The number of displacements were defined by the number of visits to the HCB during the pre-transplant workup. Mean and standard deviation (SD) were used for these quantitative continuous data.

RESULTS

The methodology applied in this study led to the identification of key points and unmet needs as well as the implementation of novel protocols and circuits. To highlight the relevance of this stepwise systematic approach, the results obtained in each step will be described separately.

To Comprehend—Understanding Patient Experience

The Professional Viewpoint: Co-Creation Workshops and Literature Review

During the co-creation workshops, patient archotyping, stakeholder and patient journey mapping and categorization of the transplant

TABLE 1 | Pre-identified areas of interest for transplant patients according to professional opinion.

Key moments during the SPKT process	Areas of interest
At the time of referral to the HCB	<p>The healthcare process that takes place at the HCB. This information must be given to the referral center.</p> <p>General information provided to each patient through HCB's Portal Clinic platform (42), QR code, etc.</p> <p>The details of the contact person before the first visit to the HCB.</p> <p>Information that should be provided by the patient: Medical report from their center of origin, diagnostic digital images.</p> <p>Legal information (especially relevant to foreigners).</p> <p>Access information for the first visit at the HCB.</p> <p>Available public services around the HCB such as the patient hotel.</p>
During the candidate assessment for SPKT	<p>Information to be given to the patient during the first visit to the HCB: All kinds of involved health professionals, the place, number and types of visits prior to the SPKT and the complementary and exploratory analyses.</p> <p>The duration of the assessment process.</p> <p>Overall information on the SPKT.</p> <p>Criteria for medical decisions.</p> <p>Contraindications of the SPKT (obesity, etc.).</p> <p>Patients at risk: Nutrition, smoking habit, alcohol, addictions, etc.</p> <p>Social acceptance.</p>
During the waiting time and at the time of transplant surgery	<p>Time management until the surgery date. Important topics to be addressed: Prioritization criteria and possible unexpected complications during the assessment and waiting period, given that they are fragile patients.</p> <p>Follow-up during the waiting period (analyses and periodic explorations) and contact channel for possible clinical incidents.</p> <p>Removal of the donor organ and viability assessment: Safety criteria and risk of donor incompatibility at the last moment (50% of patients cannot receive the organ after the first call).</p> <p>Informed consent before acceptance onto the patient waiting list for transplantation.</p> <p>Events that take place the day of the call (immediately getting to the HCB) and analyses that need to be carried out and/or repeated.</p> <p>Information for the caregiver.</p>
At hospital discharge and follow-up	<p>Pharmacological treatment: Lifelong prescriptions, adherence and secondary effects (vision, blood pressure, skin, tremor, etc.).</p> <p>Changes in nutritional habits (such as increased appetite) and food safety.</p> <p>Everyday life: Travelling, pets, vaccinations, and sexual and physical activity.</p> <p>The importance of smoking cessation.</p> <p>Follow-up information during outpatient care: First quarter, first year and thereafter.</p> <p>Benefits of shared follow-up with doctors and nurses and how this will take place.</p> <p>Contact details (email and phone).</p> <p>Warning signs and symptoms (infection and rejection).</p> <p>Asymptomatic hypoglycemia.</p> <p>Maintaining diabetes under control and possible complications (endocrinologic, cardiac, ophthalmologic, etc.).</p>

HCB, Hospital Clinic Barcelona; SPKT, simultaneous pancreas-kidney transplant.

process were carried out by professionals to identify potential key steps for patients undergoing a double pancreas-kidney transplant.

Based on the literature review and professional experience, professionals classified pancreas transplant candidates into a number of archetypes, according to age (<45 or >45=years), residence zone (Barcelona, Catalonia or other autonomous regions), social and family support (good or dependent), Body Mass Index (BMI) (BMI > 27: High or BMI < 20: Low), vascular complications (micro or micro and macrovascular) and type of DM (T1DM or T2DM). Patient

archetypes were used to select focus group participants to assure representation of all archetypes during the sessions.

The major stakeholders in our healthcare system were mapped as: Professionals from different medical specialties, from other disciplines and from public and private research and industry; policy-makers and society at large (including patients and caregivers). While defining the patient journey, three main dynamics were taken into consideration. Firstly, referral from multiple centers implies an administrative burden. Secondly,

TABLE 2 | Collected data during the focus group session on information and healthcare assistance.

Meta-category	Category	Results	Selected patient quotations
Contact and Communication	Contact via telephone	Most of the patients do not require any phone calls for urgent issues. Nevertheless, if that happened, they would like quick and effective telephone access.	<i>I think that, if I were involved in an urgent situation, I would try to call the hospital.</i>
	Contact via email	It was highly rated by those who used it, although they would appreciate a quicker reply (<48 h).	<i>I send emails to the Unit now and then when I have doubts. They don't reply immediately, they take a couple of days, but they usually reply.</i>
	Displacements to the hospital (pre- and post-transplant)	The pre-transplant phase does not require many displacements. After the procedure, they go through check-ups every 4–5 months, which usually require less than a day. Also, due to the COVID-19 pandemic, patients try to avoid public transportation.	<i>I have scheduled visits every 6 months or so with the endocrinologist at the HCB, but I see my private ophthalmologist and the rest of the specialties here in San Sebastián.</i>
	Communication between hospital of origin and HCB	Inter-hospital miscommunication was mentioned and some patients experienced issues with the transfer of their files. This caused longer waiting times and more anxiety. A shared digital platform for medical histories was suggested to ease data access and increase health system efficiency.	<i>My endocrinologist recommended medical consultation with the HCB for this type of intervention. I underwent several tests for 2 years and when my file was ready to be transferred, it got lost and had to be redone. It was such a long process [. . .].</i>
Information	Previous information	Most patients agreed that the information they had received about the SPKT was clear and honest but probably not enough, especially for highly vulnerable patients.	<i>I mean receiving more information such as what a double transplant is, etc. [. . .] As you can well imagine, when they tell you that [the need for a double organ transplant] you have no other choice than to adapt and make plans for a new life. In my case, I needed much more information. . . .</i>
	Information on waiting time	There is room for improvement here too. Patients would like to have more knowledge of the waiting time. Even rough estimates would be useful to be psychologically more prepared and better organize their everyday lives.	<i>I didn't feel anxious while waiting, but I would have preferred a bit more extra time to conclude some matters or to better plan them. For example, the week before the transplant I bought a car and right before getting to the HCB I had to deal with some paperwork. If I had known a month in advance about the possibility of an imminent organ donor, I would have postponed my purchase. You have your own life and events continue to unfold, but the moment you receive the call you're certain that it will all change [. . .].</i>
Waiting time	Waiting time	There was a great variety of opinions. Those who had added health complications or came from far away recalled a long wait.	<i>In my case, I received the first transplant very quickly, but then I rejected it and had to wait over 5 years for the second one.</i>
	Consequences of waiting time	The majority of patients were convinced that longer waiting times have physical consequences. Some of them have experienced it. As a result, they stressed the importance of receiving the new organs as soon as possible.	<i>People tend to associate diabetes with a different lifestyle, but they forget about all the problems that may suddenly arise. In my case, one of my feet burst, my vision got worse and I don't know what else I could have had. Maybe, if the waiting time had been shorter, we would have avoided or minimized such events. On the other hand, I understand that other surgeries are going on at the same time. . . .</i>
Impact on patients' everyday life	Family and social awareness	Having a serious illness and going through such a delicate procedure helps increase awareness.	<i>I have experienced it in my family too. They now see organ transplantation very differently. My friends from the swimming club now give blood. People are more conscious if they know of someone who is going through that.</i>
	Improvements in working life	SPKT improves patients' professional life too. They were able to work afterwards.	<i>I started working for ONCE as a lottery ticket seller. I became blind in 2008, I started dialysis in 2010, I was transplanted in 2013 and then, 4 years later, I found this job. I am entitled to a disability pension, but I can work and honestly, this makes a tremendous difference.</i>
	Transplants that are finally not performed	The fact that sometimes pre-scheduled transplants cannot be performed cause a great deal of distress to patients. Still, they are sympathetic towards medical decisions.	<i>This is hard. I had reached an impasse right before the second transplant, but I was on the reserve list and nonetheless I had to go home. "We will call you back," they say. Another year. . . .</i>
	Psychological support	Patients agreed to receiving emotional support, especially during (but not limited to) the waiting time and after the transplant in order to adjust to new living and working conditions. Psychological aid may be appropriate.	<i>I finally relaxed, but you pay for all the stress that you have suffered during the previous months. Then I was alone, and it took me a while before I realized I was depressed.</i>

(Continued on following page)