

# Testimonies and experiences of patients awaiting transplant and transplanted patients in Italy: a survey aiming to understand their needs

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## Abstract

**Introduction and methods.** In 2020 the Italian National Transplant Centre (Centro Nazionale Trapianti, Istituto Superiore di Sanità, Rome, Italy) launched two online surveys to explore waitlisted and transplanted patients' needs.

**Results.** The analysis of two-year results shows prevailing feelings of anxiety and discouragement (44.5%) in waitlisted patients. A mere 19.7% expresses feelings of trust and hope. Conversely, in transplanted patients, gratitude (65.7%) predominates. Both transplanted (53.5%) and waitlisted patients (41.5%) worry about organ rejection and complications, SARS-CoV-2 pandemic was an additional concern. The latter report certainty of transplant as their main need (81.3%), followed by psychological support (41.8%) also indicated by 27.9% of transplanted patients, while donor-recipient anonymity is an issue for 31.3% of the transplanted.

**Conclusion.** Focusing on the needs and, above all, taking them on, means putting the patient at the centre of care and increasing the chances of a better life despite sufferings and preoccupations.

## Key words

- testimonies
- needs
- waitlisted patients
- transplanted patients
- national survey

## INTRODUCTION

Testimonies and experiences of transplanted or waitlisted patients represent the best approach to understand their needs and implement the necessary actions for their fulfilment: this was the initial goal of the research. However, with the progressive spreading of the SARS-CoV-2 virus, the paradigm inevitably changed.

We had to face a reality nobody was ready for. Hospital professionals were challenged with unpredictable situations of great emotional impact. Outside the healthcare facilities, citizens lived in an unimaginable world of quarantine, social distancing and fear of infection.

Moreover, the widespread feeling of uncertainty, generated by the pandemic, was exacerbated by the perception that our healthcare system, as well as that of other countries [1], was not prepared for an emergency of this magnitude; let alone the dramatic death toll, rate of infections and a never-reassuring global media coverage [2].

All this had a disruptive effect on the entire population with tragic consequences for the most fragile, who also suffered enormously from social isolation

and the difficulties of accessing healthcare facilities [3], on top of having to pay the highest direct price in terms of lost lives. No doubt, transplanted or waitlisted subjects might have as well risked and experienced the same hardships encountered on a global scale [4]. The current study should, therefore, be framed within an anomalous and greatly concerning context, which might have affected the experience and feelings of the participants, transforming the initial cognitive objective of the research into a cross-section of such a dramatic reality.

Nevertheless, the themes for reflection offered are numerous and of great interest, along with the propensity shown by a substantial amount of the interviewed participants to interact with the system through their testimony and experience; two sharply different situations, in some respects, for those awaiting transplant and those who already received one. An example is the time on the waiting list which is different for the two groups. On the contrary, in some other matters, feelings and moods are shared by both groups, despite their experiences being completely distinct.

Many answers prove what has been described and each would be worthy an in-depth debate and consideration. The survey is however still ongoing and the urgency to limit the analysis to those aspects that might be more easily corrected, resulted in the postponement – to the end of the research – of a further analysis of other components affecting the treatment path. It is also possible to go through all answers on the Italian National Transplant Centre's (Centro Nazionale Trapianti, CNT) website at <https://www.trapianti.salute.gov.it/trapianti/homeCnt.jsp>.

**MATERIALS AND METHODS**

Since April 2020, the CNT – in collaboration with the National Heart Transplant Association (Associazione Trapiantati di Cuore, ATCOM) – launched a random sampling national survey on the experiences of transplanted and waitlisted patients, through two specific questionnaires. The survey is part of a broader research project focused on how transplant patients are managed, from waitlist enrolment to post-transplant follow up. This multi-center, retrospective, observational project was born thanks to a collaboration agreement between ATCOM and CNT, with the initial aim to create the first national register of volunteering associations working in this field and then further investigate the main need of waitlisted and transplanted patients, in order to identify necessary measures for their care pathway.

Each questionnaire, accessible online, asks 19 qualitative and quantitative questions, some of demographic nature, some other epidemiological and clinical-managerial and others aimed at exploring anxieties and needs (Figure 1 and 2). The latter are those this study specifically addresses. Most questions are closed-ended, while

others are mixed and multi-response. The last one is open and it gives the participants the opportunity to express their critical thought and their unconditional opinion. The identification of the survey topics was planned to be translated into well definite questions; its organization is meant to meet a set of rules directed at safeguarding anonymity, standardization, comprehensibility and conformity to the object of the study.

Both were submitted to a pool of experts (psychologists, epidemiologists) in order to evaluate their structure and content. In particular, three basic aspects were verified:

- level of structuring of the questions (closed, semi-structured, open);
- language used (consistency, precision, relevance, simplicity);
- formulation and questions' order.

The initiative was then presented to the actors of the transplant network (regional and transplant centres), so that they could disseminate and support it in their territory. The CNT and the ATCOM made available, on their institutional websites and social media pages, the link to the questionnaires accompanied by a presentation note for further promoting the initiative. These measures have been instrumental in increasing the number of participants, reaching over 50 questionnaires filled in a day.

For these reasons, the deadline for filling the questionnaires was postponed from December 31<sup>st</sup>, 2020 to December 31<sup>st</sup>, 2021 especially due to the participants' repeated references to the pandemic. This last aspect led us to modify the initial questionnaires while work was in progress, with the introduction of new specific questions on the topic. We expanded the number

**Assessment form of the WAIT-LISTED patient's need**

- 1. Please, indicate your age range**  

< 18 years old	19-30 years old	31-60 years old	> 60 years old
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- 2. Indicate your gender**  

Male	Female
<input type="radio"/>	<input type="radio"/>
- 3. Indicate your blood type**  

0 pos	0 neg	A pos	A neg	B pos	B neg	AB pos	AB neg
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- 4. Indicate your region of residence**
- 5. Awaiting transplant of:**  

Kidney	Liver	Heart	Lung	Heart-Lung	Pancreas	Kidney-Pancreas	Intestine	Other (specify)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- 6. Type of transplant**  

First transplant	Re-transplant
<input type="radio"/>	<input type="radio"/>
- 7. Regions where you enrolled on the list (for kidney, please indicate the two enrollments permitted)**  

First enrollment	Region	Second enrollment	Region
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
- 8. How long have you been wait-listed? (for kidney, time runs from first enrollment)**  

< 1 anno	13-24 months	25-48 months	> 48 months
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- 9. Have you faced issues during your treatment path?**  

NO	YES
<input type="radio"/>	<input type="radio"/>
- 10. If YES, which of the following?**  

<input type="radio"/> Clinical
<input type="radio"/> Logistical
<input type="radio"/> Economic/Financial
<input type="radio"/> Family related
<input type="radio"/> Work related
<input type="radio"/> Social
<input type="radio"/> Other, specify _____
- 11. How would you rate the medical staff who treated you, as far as their expertise is concerned?**  

<input type="radio"/> Extremely professional
<input type="radio"/> Very professional
<input type="radio"/> Moderately professional
<input type="radio"/> Sufficiently professional
<input type="radio"/> Not at all professional
- 12. Among the following logistical situations, which one/ones would be of bigger concern if you had to go out of your region for the transplant procedure or the required assessments?**  

<input type="radio"/> Travel planning
<input type="radio"/> Accompanying relatives' accommodation
<input type="radio"/> Economic/financial aspect
<input type="radio"/> Being separated from a familiar environment
<input type="radio"/> None
<input type="radio"/> Other, specify _____
- 13. What is your most recurring mood or thought throughout the wait?**  

<input type="radio"/> Fear of not making it
<input type="radio"/> The duration of the wait
<input type="radio"/> Concerns for family members
<input type="radio"/> Anxiety and discomfort
<input type="radio"/> Economical/financial concerns
<input type="radio"/> Trust and hope
<input type="radio"/> Other, specify _____
- 14. What is your main concern about the transplant?**  


<input type="radio"/> The surgical procedure
<input type="radio"/> The quality of the organ
<input type="radio"/> The therapy to undergo
<input type="radio"/> Organ rejection and other complications
<input type="radio"/> None
<input type="radio"/> Other, specify _____
- 15. Among the following opportunities, which one/ones would you find more helpful now?**  

<input type="radio"/> Psychological support
<input type="radio"/> Economical support
<input type="radio"/> Knowing the path to follow
<input type="radio"/> Certainty of transplant
<input type="radio"/> Work continuity
<input type="radio"/> None
<input type="radio"/> Other, specify _____
- 16. Do you think that transplant volunteer associations play an important role in supporting the patients?**  

<input type="radio"/> Very important
<input type="radio"/> Quite important
<input type="radio"/> A little important
<input type="radio"/> I do not know
<input type="radio"/> Other, specify _____
- 17. As of right now, how is your health?**  

<input type="radio"/> Good
<input type="radio"/> Decent
<input type="radio"/> Bad
<input type="radio"/> Terrible
- 18. How much does your clinical condition impact your daily life and social relationships?**  


<input type="radio"/> A little
<input type="radio"/> Enough
<input type="radio"/> A lot
- 19. Observations (Tell us about any thought you might have or situation you might have encountered that was not included in the questionnaire)**



**Figure 1**  
Survey form for the waitlisted patients.

**Assessment form of the TRANSPLANTED patient's needs**

- Please, indicate your age range**  
 <18 years old     19-30 years old     31-60 years old     > 60 years old
- Indicate your gender**  
 Male     Female
- Indicate your blood type**  
 O pos     O neg     A pos     A neg     B pos     B neg     AB pos     AB neg
- Indicate your region of residence** \_\_\_\_\_
- Specify the type of transplant received:**  
 Kidney     Liver     Heart     Lung     Heart-Lung     Pancreas     Kidney-Pancreas     Intestine     Other (specify) \_\_\_\_\_
- Indicate the type of donor**  
 Deceased donor     Living donor
- Indicate the region where the transplant was performed** \_\_\_\_\_
- How long were you wait-listed before you received your transplant?**  
 < 1 Year     13-24 months     25-48 months     > 48 months
- Which of the following situations made you feel more anxious while you were wait-listed?**  
 Clinical conditions  
 Fear of dying  
 Concern for family members  
 The duration of the wait  
 Economical/financial aspect  
 The thought of not being able to do the things I used to do before the disease  
 The future  
 I did not experience any anguish  
 Other, specify \_\_\_\_\_
- How would you rate the medical staff who treated you, as far as their expertise is concerned?**  
 Extremely professional  
 Very professional  
 Moderately professional  
 Sufficiently professional  
 Not at all professional
- Have you faced issues during your treatment path?**  
 NO     YES
- If YES, which of the following?**  
 Clinical  
 Relation with medical staff  
 Economic/Financial  
 Work related  
 Family related  
 Other, specify \_\_\_\_\_
- Which of the following situations worries or upsets you most right now?**  
 Organ rejection and complications  
 Concern for family members  
 Adherence to therapeutic plan  
 Economical/financial aspect  
 Being unable to know anything about the donor or their family  
 I am neither worried nor upset  
 Other, specify \_\_\_\_\_
- Rate the clarity of the information you received for managing the post-transplant period?**  
 Very clear  
 Clear enough  
 Sufficiently clear  
 Not clear at all
- Of the following feelings, which one/ones do you perceive more often?**  
 Fear  
 Anxiety  
 Excitement  
 Gratitude  
 Elation  
 Other, specify \_\_\_\_\_
- Among the following opportunities, which one/ones would you find more helpful now?**  
 Psychological support  
 Economical support  
 Continuous assistance  
 Knowing the care path to follow and the reference persons  
 Occupation/work  
 I do not know  
 Other, specify \_\_\_\_\_
- Do you think that transplant volunteer associations play an important role in supporting the patients?**  
 Very important  
 Quite important  
 A little important  
 I do not know  
 Other, specify \_\_\_\_\_
- As of right now, how is your health?**  
 Very good  
 Good  
 Decent  
 Bad  
 Terrible
- Observations (Tell us about any thought you might have or situation you might have encountered that was not included in the questionnaire)**  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_



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**Figure 2**  
Survey form for the transplanted patients.

of questions in each questionnaire to 32, making the integrations operational from February 1st, 2022. All this has transformed the initiative from a time-limited survey to a permanent monitoring tool, so much so that the questionnaires are still online. Consequently, being the situation an evolving one, any consideration formulated in this article might change over time.

Due to the dynamic nature of the responses, it was therefore necessary to establish a time limit within which to start an initial processing of the observed data. The present analysis is therefore based on the questionnaires received by April 30th, 2022 and only refers to the 19 initial questions, so far excluding those that were added afterwards.

## RESULTS

From 10 April 2020 to 30 April 2022, 8,899 participants joined the research, i.e., 14% of all patients registered in the Italian Transplant Information System (SIT) waiting for transplant in the study period or followed up post-transplantation, out of which 5,289 transplanted patients and 3,610 waitlisted ones, with an average age of 44.9 years old, mostly males (54.8%). A mere three foreign patients (0.08%) enrolled on the Italian waiting listed took part, and 50 Italian patients transplanted abroad (0.94%). Nationality has not been therefore taken into account in subsequent analysis due to lack of worth in the analyzed population.

Kidney patients are the most represented both among waitlisted (60.1%) and transplant recipients (39.6%), making up 47.9% of the entire sample. This percentage rises to 51% including kidney-pancreas (or nephropathic patients). Hepatopathic (25.5%) and cardiopathic patients (14.6%) follow. Patients transplanted or await-

ing lung (6.1%), pancreas and kidney-pancreas (4.2%), tissue (1.6%) and heart-lung transplantation (0, 04%) complete the series with lower percentages (Table 1).

In general, a sense of discouragement prevails among waitlisted patients, especially due to the long waiting times (59.2%). Many of them even believe that they will not make it (30.9%) and only 19.7% report positive feelings of trust and hope. The fear of dying is common among those waiting for a lung or a heart, indicated by 60% of the former and 52.9% of the latter (Table 2). 70% of the latter also indicate surgery as their greatest worry as far as transplantation is concerned, a percentage that increases to 77% among females (Table 5). Time on the list is a particularly felt issue among patients expecting a pancreas (74.6%) or a kidney (65.2%). Both are also the most disheartened, since only 16.2% of the former and 19.4% of the latter picked "feeling hopeful" as a response (Table 2). Among already transplanted patients, gratitude prevails (65.7%), although anxiety (44%) and fear (18.2%) indicate a distress common to 62.2% of patients. This is found in all participants regardless of the transplant they underwent. Liver transplant recipients are particularly grateful (70.7%), while pancreas transplant recipients (51.6%) are the most anxious. Conversely, "serenity" is poorly reported by all participants, indicated by a mere 2.8% (Table 3). It should be noted that, for all multiple-choice questions, the number of answers is not equal to the number of respondents, since more options can be ticked. Therefore, the answers can apparently reach a higher-than-100% percentage.

The testimonies of those directly involved are also notably different when it comes to the waiting time. The answers analyzed so far show that 77.8% of transplant

**Table 1**

Patients responding to the survey on the waiting list or transplanted by organ

Organ/tissue	Waitlisted patients		Transplanted patients		Global case history	
	N.	Ratio (%)	N.	Ratio (%)	N.	Ratio (5)
Kidney	2,168	60.1	2,097*	39.6	4,265	47.9
Liver	563	15.6	1,702	32.2	2,265	25.5
Heart	463	12.8	836	15.8	1,299	14.6
Lung	190	5.3	352	6.7	542	6.1
Pancreas	67	1.9	31	0.6	98	1.1
Kidney-Pancreas	105	2.9	174	3.3	279	3.1
Heart-Lung	3	0.1	1	0.01	4	0.04
Tissue	51	1.4	96	1.8	147	1.6
Total cases	3,610	40.6	5,289	59.4	8,899	

\* It includes 11 double kidney transplants.

**Table 2**

Answers to the question: "What is your most recurring mood or thought throughout the wait?"

Answer	Waitlisted patients					
	All (%)	Kidney (%)	Liver (%)	Heart (%)	Lung (%)	Pancreas (%)
Wait length	59.2	65.2	49.9	45.4	45.3	74.6
Anxiety/discouragement	44.5	53.9	27.7	25.1	35.8	65.7
Fear of not making it	30.9	19.9	45.3	52.9	60	34.3
Trust/hope	19.7	16.2	23.1	28.5	23.7	19.4
Concern for family members	19.4	19.9	20.2	19.9	14.2	14.9
Economic concerns	10.9	11.4	12.8	9.5	5.8	9
Surrender	3.9	4.8	2.3	2.2	1.6	3
Other	12.2	11.9	9.1	11.0	28.9	16.4

Answer by gender	M (%)		F (%)		M (%)		F (%)		M (%)		F (%)	
	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)
Wait length	57.5	61	64.3	66.1	50.6	48.9	46	44.2	44.1	46.4	71.4	76.9
Anxiety/discouragement	42.1	47.1	49.6	57.7	25.1	31.4	26.2	23	36.8	34.7	64.3	66.7
Fear of not making it	31.8	30	19.4	20.4	44.6	46.3	52	54.5	60	60	32.1	35.9
Trust/hope	20.5	18.9	17.5	15.1	23.1	23.1	26.8	31.5	21.1	26.3	17.1	21.5
Concern for family members	19.1	19.6	18.3	21.4	21.6	18.3	19.5	20.6	18.9	9.5	14.3	15.4
Economic concerns	13.4	8.3	13.9	9.2	15	9.6	12.4	4.2	9.5	2.1	17.3	2.6
Surrender	2.9	4.9	3.4	5.9	2.1	2.6	2	2.4	3.2	0	0	5.1
Other	11.5	12.9	11.2	12.6	8.7	9.6	11.1	10.9	26.3	31.6	28.6	7.7

recipients report having received the transplant within 24 months of enrollment on the list. The percentage rises to 91.7% for liver transplant recipients, while 52.7% of patients currently on the list have been waiting for more than 24 months, with cases exceeding 5 years. The overall figure is probably influenced by the large number of renal patients, who are the majority of participants in the survey (60.1%). Among these, the number of those who have been on the waiting list for more than 24 months is over 60%. For the other types of transplant, there are no large differences in waiting times between those on the list and transplant recipients (Table 4).

There are other situations, where the experiences of the two groups coincide or differ less. Anxiety, for example, is a condition common to many patients on the list (44.5%) and particularly frequent among those expecting a kidney (53.9%), but the same emotional state is also experienced by transplant recipients (44%). This data is also reflected by the answers to the next question of the questionnaire *Among the following opportunities, which one/ones would you find more helpful now?* In this case, transplant recipients ticked as their most desired form of help "continuous assistance" (33.7%), followed by "knowing the care path to follow" (32.1%) and "psychological support" (27.9%). The latter is also indicated

**Table 3**

Answers to the question: "Of the following feelings, which one/ones do you perceive more often?"

Answer	Transplanted patients											
	All (%)		Kidney (%)		Liver (%)		Heart (%)		Lung (%)		Pancreas (%)	
Gratitude	65.7		61.2		70.7		68.8		66.2		54.8	
Anxiety	44		47.7		38.7		44.3		46		51.6	
Fear	18.2		19.7		15		20.2		18.2		29	
Enthusiasm	11.7		11.2		9.7		12.9		17.3		19.4	
Uncertainty/insecurity	8.9		7.7		9.5		9.1		8.5		9.7	
Elation	4.6		4		5.2		5.4		4.8		3.2	
Peacefulness	2.8		2.5		3.3		3.2		1.4		0	
Other	6.6		6		6.8		6.8		9.1		3.2	
Answers by gender	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)
Gratitude	65.1	66.4	60.5	62	71.7	68.7	67.7	70	64.7	67.8	57.1	52.4
Anxiety	43.1	45.7	46.1	49.6	37	40.4	42	47.5	43.1	49	49.7	53.4
Fear	16.1	21.2	17.5	22.1	13	18.8	17.8	23.8	17.9	18.5	26.7	31.3
Enthusiasm	12.5	10.6	12.5	9.8	10.4	8.4	13.1	12.6	17.9	16.8	22.6	16.3
Uncertainty/insecurity	7.8	10.3	6.8	8.6	9.7	9.1	8.3	11.2	6.6	10.6	8.7	10.5
Elation	4.7	4.3	4.1	3.8	4.9	5.7	5.7	5	6.1	3.5	4.6	2.2
Peacefulness	2.2	3.6	1.7	3.4	2.5	4.7	2.2	4.7	1.7	1.2	0	0
Other	6.8	6.4	5.9	6.2	6.5	7.2	8.3	4.7	10.1	8.1	4.1	2.4

**Table 4**

Answers to the question: "Time spent on the waiting list"

	All	Waitlisted patients					Transplanted patients					
		Ki (%)	Li (%)	He (%)	Lu (%)	Pa (%)	All (%)	K (%)	Li (%)	He (%)	Lu (%)	Pa (%)
<24 months	52.7	39.9	82.8	71.3	66.4	31.3	77.7	62.7	91.7	87.7	80	80.7
>24 months	47.3	60.1	17.2	28.7	33.6	68.7	22.3	37.3	8.3	12.3	20	19.3

as a service that is often not offered by the system but as a need fulfilled through the patient's personal initiative. A necessity that, among waitlisted patients, is identified by a large number of participants (41.8%) and is considered most helpful; second only to the certainty of transplantation (81.3%). The same is observed for organ rejection which represents the main concern among transplant recipients (53.5%), particularly among kidney ones (69.7%). A concern which is shared by waitlisted patients, so much so that to the question "What is your main concern about the transplant?" 41.5% of the participants replied "organ rejection" and "complications", indicating them as their greatest source of anxiety, especially those who are waiting for a kidney (50.6%) (Table 5).

Surprisingly, the second most frequent answer to the same question among transplant recipients is *being unable to know anything about the donor or their family members*, which was indicated by 1,646 patients, i.e., 31.1% of the participants (Table 6). This data is also confirmed by the provided open answers and gains even more relevance if analyzed by type of transplant and by gender. Among liver transplant recipients, the regret for the

lack of information about the donor and their family is indeed indicated by 37.7% of the participants and, among them, especially by females (41.5%). The same goes for heart transplant recipients, where it is indicated by 39.7% of patients, 45.5% of whom are females. The anguish caused by the lack of information about the donor and their family, is even greater, among recipients of these two types of transplant than the fear of organ rejection and it is reported by 38.3% of heart transplant recipients and 36.8% of liver transplant recipients.

Another common thought among participants of both surveys is the strong reference to the SARS-CoV-2 pandemic as a situation of additional concern for their condition. The data was obtained from the provided open answers, which highlighted an aspect initially neglected in the questionnaires, an opportunity seized by 26.4% of the participants (2,352 patients). Of these, 11.7% explicitly refers to the pandemic and the measures taken to curb it, as disturbing and worrying factors in the respective care pathways. Questions on the subject were not initially foreseen, because no one could have imagined such a rapid and lasting evolution of COVID-19.

**Table 5**

Answers to the question: "What is your main concern about the transplantation?" (Question addressed to waitlisted patients)

Answer	Waitlisted patients											
	All (%)		Kidney (%)		Liver (%)		Heart (%)		Lung (%)		Pancreas (%)	
Organ rejection and complications	41.5		50.6		23.1		21		30		44.8	
Surgery	27.8		10.1		44.6		70		67.9		28.4	
Nothing	27.5		32.9		26.8		11.2		17.4		26.9	
Quality of organ	20.6		19		24		17.3		30		23.9	
Post-transplant therapies	10.7		10.5		13.7		9.1		7.4		11.9	
Everything	8.3		10.1		7.1		3.2		4.2		6	
Other (specify)	6.2		5.1		5.3		7.8		12.1		10.4	
Answer by gender	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)
Organ rejection and complications	40	43.1	50.7	50.5	21.6	25.3	22.1	19.9	29.5	30.5	43.5	46.2
Surgery	29.2	26.3	8.9	11.1	42.2	47.1	66.1	77	70.6	65.2	30.3	26.5
Nothing	28	27	32.7	33.1	28.2	25.4	11.6	10.4	16.8	17.9	26.8	26.9
Quality of organ	20.1	21	20.3	17.9	22.1	26.1	16.4	18.4	29.5	30.5	22.9	24.8
Post-transplant therapies	10.1	11.4	9.1	11.7	13.8	13.5	9.4	8.5	9.5	5.3	10.7	12.8
Everything	7.9	8.7	9.8	10.2	7.2	7	3	3.6	6.3	2.1	3.6	7.7
Other (specify)	6.6	5.8	5.2	5.1	5.1	5.7	9.1	5.5	12.6	11.6	14.3	7.7

**Table 6**

Answers to the question: "Which of the following situations worries or upsets you most right now?" (Question addressed to transplanted patients)

Answer	All (%)		Kidney (%)		Liver (%)		Heart (%)		Lung (%)		Pancreas (%)	
Organ rejection and complications	53.5		69.7		36.8		38.3		67		61.3	
Not knowing about the donor and their family	31.1		24.7		37.7		39.7		24.1		29	
I am not worried/upset	21		16.8		26.1		23.1		19.3		25.8	
Concerns about family members	17.6		15		19.6		23.8		14.5		9.7	
Adhering to the therapeutic program	12.8		11.3		14		15.2		11.6		19.4	
Economic/financial aspect	7.5		6.2		9.5		8		4.3		9.7	
Other	6.8		6.2		6.1		6		13.4		3.2	
Answer by gender	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	F (%)
Organ rejection and complications	50.8	56.3	64.5	75.7	34.4	41.3	39.6	36.4	62.6	71.7	53.3	68.8
Not knowing about the donor and their family	29.2	33.8	21.9	27.9	35.6	41.5	35.8	45.5	22.3	26	40	18.8
I am not worried/upset	24.6	16.3	20.4	12.7	29.4	20	23.6	22.3	24	14.5	26.7	25
Concerns about family members	17.4	18	14.2	15.8	19.9	19.2	22.6	25.5	12.8	16.2	13.3	6.3
Adhering to the therapeutic program	12	14	10	12.8	13.2	15.6	15.2	15.2	11.2	12.1	26.7	12.5
Economic/financial aspect	9	5.4	6.8	5	10.6	7.6	11.1	3.5	6.1	2.3	13.3	6.3
Other	6	8	5.7	6.9	5.1	7.9	6.1	5.9	10.1	16.8	0	6.3

However, we anticipate that from the answers received after the introduction of specific questions, i.e., from February 2022, the references of patients to impact of the pandemic have increased. In fact, to the question: *Do you think that the state of emergency due to the coronavirus pandemic (SARS-CoV-2) has influenced your*

*treatment path?* 64.8% of waitlisted patients and 33.4% of transplanted patients answered YES. The data, although preliminary, hints to the relevance of the pandemic for these groups, even if it needs to be stratified and analyzed by different variables, for its impact to be fully understood.

## DISCUSSION AND CONCLUSIONS

The themes analyzed in the study are various and all of great interest. Some, in particular, have caught our attention.

Firstly, patients' experiences, either waitlisted or transplanted, reveal a daily reality made up of shared, emotional suffering and discomfort. The reported states of mind have some deeply different traits but coincide for many others. Anxiety is one of these: it is reported by 44.2% of survey respondents from both groups, who admit to feeling constantly anxious, whether they are awaiting or already underwent transplant; this emotional state is probably influenced by the patient's feeling of uncertainty, e.g., about the transplant date or the possibility of organ rejection.

On the other hand, for waitlisted patients, the waiting period is undoubtedly difficult for several reasons: first of all, a lot of anguish is caused by the lack of a defined timing, waiting for a transplant without knowing if and when it will happen also comes with the fear that it may not take place on time or that it may not work. All this generates conflicting emotions between the desire to receive the call for the transplant and the understandable fear for the outcome of the surgery. These contrasting emotions are shown in the free answers provided by survey respondents, by the repeated references that patients make to the fear of not hearing the phone ringing (37%), or to the fear of not waking up after surgery (12%), or that the surgery may not be conclusive (11%). This is particularly frequent among patients awaiting life-saving transplants such as heart or lung.

For those who have survived the wait unscathed and received the transplant, the concern shifts to the risk of organ rejection. The state of anxiety, therefore, lingers on and is renewed with every checkup or small alarm sign. Not everyone, however, is equally anxious. Some even appear nonchalant in the face of those same situations that for others, are a source of great concern. The latter are also those who indicate psychological support as one of the greatest needs both among waitlisted patients and transplant recipients. Essentially, the state changes and so do fears, but not the want of support. This denotes a condition of persistent emotional frailty, under which it is more difficult to accept or tolerate any event beyond one's control [5]. In addition, this condition should be taken into strong consideration because, as shown in other studies, this state of frailty may expose patients to a greater risk of depression [6]. These requests for help should be answered systematically with structured and integrated support to the treatment path and not merely if advanced by the patients themselves. The fact that many of them report that psychological support is more often than not met only on request, represents one of the system's critical issue that should be corrected.

Another interesting issue is the sorrow expressed by a third of the respondents regarding the impossibility of knowing the identity of the donor or of having information about them or their family. This is still a controversial and debated topic, despite the reference law on post-mortem organ and tissue donation in our country, being clearly founded on the principle of anonymity, as

well as those of gratuity of the treatment and freedom of choice [7]. Most probably, during pre-transplant information talks, patients should be duly informed about legal provisions on anonymity of donor and recipient and verify this concept has been fully understood and accepted.

However, the evolution of both society and the Transplant Network has reopened the debate regarding the need for the current legislation to be revised precisely in the light of the changes that have taken place. The National Bioethics Committee itself has opened to the possibility that the principle of anonymity be reconsidered under certain conditions [8]. In the light of this, a legislative proposal was also presented to the Chamber of Deputies which incorporates all the suggestions of the National Bioethics Committee and, therefore, it cannot be excluded that in the near future, in Italy, contacts between donors and recipients may be allowed [9]. Documenting the position reported by over 31% of the survey participants represents an important element of knowledge and it might provide a pivotal contribution to the discussion.

What is unexpected is that the yearning for information, frequently expressed by the donor's relatives, is shared by many transplant recipients who believe the current limitation to be of social nature, both for those who just wish to leave a flower on the donor's resting place and for those who are truly tormented by the idea of not being able to personally express their gratitude to the family.

All this denotes a need for gratitude, which, although understandable, remains a delicate issue that can lead to dependence and open up scenarios of subjection that can result in a condition of fragility. It will therefore be necessary to thoroughly weigh the possible benefits of an emotionally strong relationship between the donor's family and the recipient, which comes with the high risk of both parties' expectations being disappointed, at some point. The rule that protects anonymity, even if it may seem excessively restrictive, represents a form of emotional protection both for the recipients and for the donor's family members. In the event of being able to meet, certainly neither party can be left alone, even when this will is clearly expressed by both. It is likely that the mediation of a third party, indicated by the National Bioethics Committee as one of the possible conditions, can represent an intermediate solution capable of better and more appropriately manage relationships that can prove to be very complex [10, 11].

Moving on, the wide response to the surveys (63.1% of patients who accessed the online questionnaires, equal to 14% of patients registered in SIT) testifies to their desire to interact with the system and to the isolation and difficulties exacerbated by the pandemic. However, the many comments freely formulated, whether they be of appreciation for the initiative, or questions or about critical issues, imply that we are faced with patients in need of expressing their doubts, uncertainties and of asking for explanations. All this draws attention to the importance and value of the doctor-patient relationship. Healthcare professionals should be more aware

that human qualities such as availability, ability to listen and dedication are not secondary to professional skills and, most importantly, that a greater communicative effort on their part can foster the empathic bond with the patient and improve their assistance [12].

The last aspect that emerges is the pandemic and its possible interference in the path of care of patients. According to part of the participants, the state of emergency caused by COVID-19 interfered in their care path not only as far as the risk of being infected by the virus is concerned, but also in terms of making access to treatments and care for waitlisted patients more complicated, as well as routine checkups for transplant recipients. In particular, from the answers to the specific questions introduced later in the questionnaires, 4 out of 10 patients report complications in their respective care pathways; of these, just over 2 out of 10 had difficulty in keeping in touch with specialists and reference centers for their pathology; 2 out of 10 have been struggling with practical problems such as abruptly canceled scheduled visits and exams. Among transplant recipients, the greatest difficulty relates to the reduction in checkups (55%); while among waitlisted patients to accessing diagnostic services in the area (51.8%).

From these preliminary data we can therefore conclude that the pandemic has created some concern. The hardships reported by patients make us believe that the problems can be attributable both to the state of suffering of health structures overwhelmed by the emergency, and to an attitude of caution or renouncement of patients for fear of the virus. This is a reasonable outcome, considering that these situations are also highlighted in other studies [13]. On the other hand, the feeling of being overwhelmed by the COVID-19 emergency is shared by everyone and had consequences in every field, throughout the globe. The death toll (over 6 million) and the number of infections (over 500 million) demonstrate its devastating effect [14]. It is therefore plausible that the transplant system may have been affected as well.

However, the opposite could be just as valid: the Italian transplant system has successfully withstood the emergency impact, since 6 out of 10 patients report that they have not been affected by the pandemic.

In reality, there is much left to be understood about COVID-19's effects so far and over time. Among others, our remarks are based on data freely reported by the survey participants which, although substantial in number, do not represent the entire sample of patients tracked by SIT, that is 16,822 waitlisted and 45,812 followed-up transplanted patients. At the end of the research, the results will necessarily be stratified and evaluated according to geographical area of residence of the patients and of the transplant, as well as age, type of transplant, gender and, last but not least, vaccination status.

So, even if the peak phase of the health emergency seems to be behind us and the latest variant of the virus under control, we can only make a preliminary assessment of the consequences for the Italian transplant system.

In conclusion, we can say that what we have observed

so far is a multi-faceted capital of knowledge, deserving further and specific insights. The deep sufferings emerged are what researchers define as "criticalities". These hardships, regardless of the question asked, mainly revolve around the exhausting wait and fear of organ rejection. Two distinct topics that seem to be the common thread of the patients' anxieties and needs, even if with substantial differences between transplant programs. The psychological distress probably arises from this, also due to the lack of precise indication to the professional figures to rely on. It is one of the system's shortfalls, which unfortunately foresees different approaches and solutions throughout the national territory. Strengthening the local psychological care services is a fundamental action in order to reach an effective, consistent and integrated level of care of both waitlisted and transplanted patients, given that psychological balance is an integral part of the individual's well-being. However, although this may meet patients' needs, the underlying problem is still a structural one and it is caused by the gap between supply and demand for organs that generates long waits from which anxieties and discomfort arise. Measures to support patients are, therefore, welcome but more must be done both on finding potential deceased donors, for example by consolidating the DCD (Donation after Circulatory Death) donation program (NHBD), and by providing greater support for living donation which remains an additional resource of great importance.

Prospective activities, that are planned to be implemented as output of this survey are: a) the organization of a public Webinar, during which patients and transplant network stakeholders would have the opportunity to discuss the survey outcomes and identify proper measures to be taken; b) performing a deeper analysis of collected infos, in order to select most frequent critical issues, most affected geographical areas and kind of transplant, so as to be able to prioritize interventions by Regional Transplant Centres and hospitals; c) third, analysing the impact – on patients' attitude – of organizational measures put in place by Regional authorities to support donation and transplant activities, comparing this data with the trend of utilized donors, carried-out transplant and waitlist waiting time.

Our goal so far was to intercept and report the wants of patients, but we now have to take care of them. It would therefore be very important to submit these testimonials to qualified professionals who know how to interpret their meanings and promote adequate solutions. On the other hand, the identification and interpretation of needs is a preliminary activity of fundamental importance for setting up each service or intervention program [15]. This may represent the starting point for proposing monothematic researches capable of leading us to a fuller satisfaction of needs, on the one hand, and on the other to a better organization of the transplant system, a most articulated and complex one.

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**Conflict of interest statement**

No conflict of interest to declare.

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**REFERENCES**

1. Chatterjee P, Nagi N, Agarwal A, Das B, Banerjee S, Sarkar S, Gupta N, Gangakhedkar RR. The 2019 novel coronavirus disease (COVID-19) pandemic: A review of the current evidence. *Indian J Med Res.* 2020;151(2, 3):147-59. doi: 10.4103/ijmr.IJMR\_519\_20
2. Anwar A, Malik M, Raees V, Anwar A. Role of mass media and public health communications in the COVID-19 pandemic. *Cureus.* 2020;12(9):e10453.
3. Aktas P. Chronic and rare disease patients' access to healthcare services during a health crisis: The example of the COVID-19 pandemic in Turkey. *Health Expect.* 2021 Oct;24(5):1812-20.
4. Bruchfeld A. The COVID-19 pandemic: consequences for nephrology. *Nat Rev Nephrol.* 2021;17(2):81-2.
5. Ayesta A, Valero Masa MJ, Vidán MT, Luna-López R, Segovia-Cubero J, García-Cosío MD, Pérez-Gómez L, Caravaca Pérez P, López-Ibor JV, Juch J, Martínez-Sellés M. Prevalence and characterization of frailty, depression, and cognitive impairment in patients listed for heart transplantation: Results of the FELICITAR prospective registry. *Clin Transplant.* 2021;35(9):e14391. doi: 10.1111/ctr.14391
6. Cron DC, Friedman JF, Winder GS, Thelen AE, Derck JE, Fakhoury JW, Gerebics AD, Englesbe MJ, Sonnenday CJ. Depression and frailty in patients with end-stage liver disease referred for transplant evaluation. *Am J Transplant.* 2016;16(6):1805-11. doi: 10.1111/ajt.13639
7. Italia. Legge 1 aprile 1999, n. 91. Disposizioni in materia di prelievi e di trapianti di organi e di tessuti. *Gazzetta Ufficiale - Serie Generale n. 87, 15 aprile 1999.*
8. Petrini C, Riva L, Florida G, Mannelli C. Anonymity and organ donation: Ethical and policy implications after the opinion released by the Italian Committee for Bioethics. *Transplant Proc.* 2020 Jun;52(5):1525-7. doi: 10.1016/j.transproceed.2020.01.079
9. De Santo NG, Cirillo M, De Santo LS, Abbas MH, De Rosa G, Resic H, Perna AF, Citterio F, Venditti G, Balat A, Santini L, Masullo A, Casavola FP, Zecchino O, Di Iorio B, Capasso G. Legislative proposal in Italy to facilitate contacts between deceased organ donor families and transplant recipients. *J Nephrol.* 2020;33(6):1333-42. doi: 10.1007/s40620-020-00824-y
10. Dicks SG, Northam H, Mp van Haren F, Boer DP. An exploration of the relationship between families of deceased organ donors and transplant recipients: A systematic review and qualitative synthesis. *Health Psychol Open.* 2018;5(1):2055102918782172. doi: 10.1177/2055102918782172
11. Oliver E, Moreno G, Grinyo JM. Anonymity of organ donors under discussion. *G Ital Nefrol.* 2019;36(6):2019-vol6.
12. Vinson AH, Underman K. Clinical empathy as emotional labor in medical work. *Soc Sci Med.* 2020 Apr;251:112904. doi: 10.1016/j.socscimed.2020.112904
13. Bellan M, Gavelli F, Hayden E, Patrucco F, Soddu D, Pedrinelli AR, Cittone MG, Rizzi E, Casciaro GF, Vassia V, Landi R, Menegatti M, Gastaldello ML, Beltrame M, Labella E, Tonello S, Avanzi GC, Pirisi M, Castello LM, Sainaghi PP. Pattern of emergency department referral during the COVID-19 outbreak in Italy. *Panminerva Med.* 2021;63(4):478-81. doi: 10.23736/S0031-0808.20.04000-8
14. European Centre for Disease Prevention and Control. COVID-19 situation update worldwide, as of week 19, updated 19 May 2022. Available from: <https://www.ecdc.europa.eu/en/geographical-distribution-2019-ncov-cases>
15. Engelberg Anderson JK, Jain P, Zade AM, Morris AM, Slaboda JC, Norman GJ. Indicators of potential health-related social needs and the association with perceived health and well-being outcomes among community-dwelling medicare beneficiaries. *Qual Life Res.* 2020 Jun;29(6):1685-96. doi: 10.1007/s11136-019-02410-7