


Impact of COVID-19 on Families of Pediatric Solid Organ Transplant Recipients

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Abstract

Objective The COVID-19 pandemic and lockdown measures have had a clear psychological impact on families, and specifically those with children with chronic illnesses have reported greater overloads and exhaustion. The objective of this study was to evaluate the exposure, impact and experience of the pandemic on families of pediatric solid organ transplant (SOT) recipients compared to families of healthy children and adolescents. **Methods** We recruited 96 families, 48 with a pediatric SOT recipient and 48 healthy controls, matched by child age and gender. A primary caregiver from each family responded to an online sociodemographic questionnaire and the COVID-19 Exposure and Family Impact Survey (CEFIS), which explores the exposure, impact and experience of the pandemic and lockdown on families. **Results** Exposure to the pandemic was greater in families of healthy children and adolescents. The impact was mostly negative in both groups: caregivers reported increased anxiety (76%) and mood disturbances (71.9%) and hindered quality of sleep (64.6%) and health habits (58.3%). On the positive side, family relationships improved. Qualitatively, the SOT group positively perceived isolation and established hygienic measures as protective and destigmatizing, although they reported fear of virus transmission to their child. **Conclusions** The psychological impact of the pandemic has been similar in both groups, although families of transplant recipients have protected themselves more, probably because they are used to prevention measures and they see contagion as a graver risk. Additionally, SOT recipients' families presented some idiosyncratic elements, especially a decrease in their perception of stigma associated with the medical condition.

Key words: COVID-19; family; pediatric transplantation; psychological impact; solid organ transplantation.

Introduction

Due to its level of severity and spread the World Health Organization declared the coronavirus disease (COVID-19) outbreak a pandemic (Cucinotta & Vanelli, 2020). Spain has become one of the most affected countries in Europe (Ceylan, 2020) and, when COVID-19 reached its peak, a national emergency was declared, under which a total lockdown of the entire population was imposed, followed by a progressive deconfinement afterward (Royal Decree for a state of alarm 463/2020, 14th of March).

The psychological impact of the pandemic and the resulting containment measures, in particular, quarantine, can be wide-ranging and have long-term effects (Brooks et al., 2020). For families the impact of pandemics is undeniable (Fong & Iarocci, 2020): the closure of schools, changes in family dynamics and relationships, as well as the need for parents to work from home and take care of their children simultaneously. Under these circumstances, new concerns have arisen among parents, such as the financial stability and physical health of the family, their children's isolation from peers and teachers, the management, duration, and outcomes of homeschooling or their own ability to manage the situation at home (Fontanesi et al., 2020). Conflicts at home, together with anxiety and depression levels, have increased for all family members (Orgilés et al., 2020), including children (Wu et al., 2020).

If the pandemic and its consequences represent a major burden on families (Fegert et al., 2020), there are some factors that may further increase this load: for instance, parents of children with physical or mental health conditions report more parental burnout and less perceived social support (Fontanesi et al., 2020). Parents of children with chronic illnesses, among them families of pediatric solid organ transplant (SOT) recipients, have been especially worried about how COVID-19 could impact their children's health (Menon et al., 2020).

Pediatric SOT is the treatment of choice for a large number of end-stage renal, hepatic, cardiac, or pulmonary diseases (LaRosa et al., 2011). The total number of pediatric SOT recipients in Spain is 1596 (308 the total number in Catalunya, the region in which this study was carried out) (OCATT, 2020; ONT, 2020). It is important to consider that going through a SOT process involves a change from a life-threatening disease to a chronic health condition (Annunziato et al., 2012), which requires the adoption of new habits and prevention measures (e.g., periodic follow-up appointments, frequent handwashing, wearing a mask to and

from the hospital and avoiding crowded places). Pediatric transplantation may elicit stress responses and diffuse psychopathological symptoms in children or adolescents, for instance post-traumatic stress symptoms (Inspector et al., 2004; Stuber & Shemesh, 2006). Also, parents show significant parenting stress and pre- and post-transplantation burden, results consistent with those referred to pediatric patients with chronic disease (Cousino et al., 2017).

From an organic perspective, the impact of COVID-19 in transplant recipients was largely unknown. New studies do not indicate an additional risk to child and adult immunosuppressed patients with COVID-19 compared to other comorbidities (Hage et al., 2020; Minotti et al., 2020), with intensive care unit admission and mortality rates comparable to those of the general population (Raja et al., 2021). Consensus of experts recommended continuing the established therapies (Eibensteiner et al., 2020) although the risk should be evaluated on a case-by-case basis (Pérez-Martínez et al., 2021). Moreover, the disease course of COVID-19 is often mild in pediatric populations (Göttinger et al., 2020; Ludvigsson, 2020) regardless of their immune status (D'Antiga, 2020), although a possible worsening in their usual treatment adherence and self-management should be expected (Plevinsky et al., 2020).

Zhao et al. (2020) studied the effect of COVID-19 on families with children on dialysis and kidney transplantation. Almost 80% of the participants thought that COVID-19 negatively affected their child's treatment, and a higher prevalence of depressive and anxiety symptoms among caregivers was found. Also, in an online survey addressing parents of pediatric liver recipients, major concerns were early recognition of COVID-19 symptoms, doubts regarding a worse outcome in their child if infected, the impact on the child if parents were working in the medical field, and availability of medication during lockdown (Menon et al., 2020). Also, previously affected psychosocial aspects of SOT recipients (e.g., peers' acceptance or illness intrusiveness) (Fredericks et al., 2014) could be exacerbated by a more severe isolation or the reported extra fear of contagion.

Although research has not indicated a worse medical prognosis in the case of SOT recipients who have been infected with COVID-19 (Goss et al., 2021), a negative effect on patients' or caregivers' mental health could be expected (Hage et al., 2020). In a context of total uncertainty for transplant recipients and caregivers (Massey & Forsberg, 2020), issues such as fear of contagion, difficulties accessing hospital care

settings or transplant-specific concerns about health-habits prevention can be a major cause of stress in the families of immunosuppressed patients.

The aim of this study was to evaluate and compare the exposure, impact, and experience of COVID-19 on the families of SOT recipients and healthy controls. We hypothesized that SOT recipients' families would be less exposed to COVID-19, although the current situation of the pandemic may produce a greater psychological impact on them. Moreover, we aimed to explore the personal experiences of families of SOT pediatric recipients and to compare them with families of healthy children and adolescents.

Methods

Context

In Spain, a State of Alarm was declared from March 13 until June 21, 2020. A strict home lockdown was imposed (in-person educational, commercial, and social activities were suspended, only essential jobs were allowed to continue their activity), which was kept in place until early May ([Royal Decree for a state of alarm 463/2020](#), 14th of March). At that time a deconfinement process was started and carried out in 4 phases. The main changes in Catalunya, were as follows: Phase 1 (starting May 11) allowed people to leave home to visit relatives; Phase 2 (starting May 25) allowed bars, restaurants and larger stores to open; Phase 3 (starting June 8) allowed higher mobility between different geographical areas; Phase 4 (starting June 22), a period also informally known as “new normality”, allowed free mobility and social gatherings, but several restrictions remained in place, such as social distancing, mandatory masks in public places and limitations on occupant capacities for commerce and public events. In late July, recruitment of the sample began, and data collection was conducted over 31 days, during August 2020. At that time, there was an uptick in new cases of COVID-19 (6043 new cases in one week in Catalunya) while mortality rates remained low (7 deaths in 1 week). This increase was the start of what would later be known as the “second wave” ([Centro de Coordinación de Alertas y Emergencias Sanitarias, 2020](#)).

Participants

The total study sample consisted of 96 caregivers, 48 of whom represented families in which one member had undergone a pediatric transplant process (SOT group) and 48 families of healthy children and adolescents (control group). Inclusion criteria were: (1) being an adult caregiver in a family of a pediatric patient, 18 years of age or younger, who had gone through a SOT (renal, hepatic, cardiac, or pulmonary), (2) being an adult caregiver in a family with a children or

adolescent without chronic illness, 18 years of age or younger, (3) having user-level computer skills, and (4) agreeing to take part in the study. Language barriers in respondents were set as exclusion criteria, as the used questionnaire was in Spanish. The approval of the Ethics Committee (PR(AG)271/2020) of the Hospital Universitari Vall d'Hebron was obtained for the research.

Procedure

We used convenience sampling, recruiting as many participants as possible in a 1-month period to capture a concrete moment within a constantly changing environment. The sample of the SOT group was obtained through families of consecutive patients who consulted the different pediatric transplant teams (hepatic, renal, cardiac, and pulmonary) at the Hospital Universitari Vall d'Hebron in person or on-line. These caregivers were contacted once by email, enabling remote adapted recruitment methods, as face-to-face contact was not recommended ([Stiles-Shields et al., 2020](#)). The email included access to a web survey application where information regarding the study (study goals, participation rights, and data treatment procedure), the sociodemographic questionnaire and the assessment instrument were provided. Caregivers could only complete the survey after having given their electronic consent to participate. Of the 120 caregivers belonging to a family with a SOT recipient that were contacted, 48 ended up responding to the full survey (40% answer rate).

To recruit the control group participants, all the SOT group families agreed to remit the received email to three to five families with a child of the same age and gender as their child. They sent it to a total of 161 caregivers of healthy children of whom 89 answered (55.3% answer rate). Control group participants were matched with SOT group participants by children's age and gender and were selected in order of response.

Instruments

The following data regarding the socio-demographic and clinical characteristics of the primary caregiver were collected: age, gender, education level, number of children, and relationship with the child or adolescent. Regarding the child or adolescent, the following information was requested: age, gender, and the basic disease for which the child or adolescent had required the transplant, type of pediatric SOT, age, and years since the transplantation, if applicable. Age at transplantation was collected as studies point out that younger age is associated with more negative parent and family functioning ([Cousino et al., 2017](#)). Moreover, the time since transplantation was included because, in the early post-transplant years, families face many challenges that may impact the entire

family system (Brosig et al., 2014), which could be exacerbated in the COVID-19 context.

The *COVID-19 Exposure and Family Impact Survey* (CEFIS), to be completed by a caregiver, was also administered. This instrument was developed by the [Center for Pediatric Traumatic Stress \(2020\)](#), using a rapid iterative process, in late March/early April 2020. The CEFIS is available in English and Spanish. It conceptualizes exposure to potentially traumatic aspects of COVID-19 and assesses the impact of the pandemic on the family, evaluating exposure, impact, and personal experience of COVID-19 in the family. The section on exposure consists of 25 items with dichotomous responses (yes/no) that measure the participants' degree of exposure to COVID-19 and related events. The Total Exposure score is the sum of all the items. The section on impact consists of 12 items: 10 items use a four-point Likert scale (with a "doesn't apply" choice also available), rating the impact on participant's and family's life, and 2 items use a 10-point distress scale. The Total Impact score is the mean of the 10 first items. As the authors indicate, several items (particularly Items 3, 4, and 5) received especially high missing or not applicable values because of their content, and cases with four or more missing responses were excluded from the computation of the Total Impact score. Higher scores indicate greater levels of exposure and impact. The last part, personal experience, is an open-ended question inviting the participant to describe the positive or negative effects of COVID-19 not covered in other questions. The CEFIS asks the respondents to answer based on what they experienced in the period from March 2020 to the moment of answering the survey, therefore encompassing the full period since the pandemic's repercussions began to be felt in Western countries.

Data Analyses

Quantitative Data

All quantitative data collected were analyzed using the SPSS version 21.0. Chi-Square tests were run to compare outcomes between groups in qualitative variables and Student's *t*-tests in quantitative variables. Pearson correlations were calculated between variables and Cohen's *d* was computed for effect sizes. To avoid Type I error, the Bonferroni correction for multiple testing was also used.

Qualitative Data

All qualitative data were collected from the open-ended CEFIS question "please tell us about other effects of COVID-19 on your child/children and your family, both negative and/or positive". An exploratory thematic analysis was performed to analyze all qualitative data, no prior hypotheses were considered, using an inductive approach (Braun & Clarke, 2006).

The researchers E.C.P. and M.F.P. independently analyzed all data with the support of the Atlas.ti program, and several themes were extracted. After the first analysis, a third investigator (C.D.) compared and triangulated outcomes and identified shared aspects. All discrepancies were resolved through consensus by all three researchers.

Results

Quantitative Results

Sociodemographic characteristics of caregivers and children in each group can be seen in [Table 1](#). All caregivers who responded were the children's parents, mostly mothers (80.2%); 52.1% of the children were boys and the average age of the child sample was 8.6 ± 4 years (with an age range from 0 to 17 years old). The SOT group included 20 liver, 17 kidney, 10 heart, and 1 lung pediatric recipients. No significant differences were found in any of the variables between the two groups.

Exposure

[Table 2](#) summarizes the quantitative data extracted from the CEFIS related to exposure to consequences of COVID-19 and associated mitigation measures. Regarding the total exposure score, the control group reported significantly higher scores than the SOT group. The areas most affected by the lockdown measures were home and family, education, and work. Although half of the families experienced a decline in income, none made reference to difficulties obtaining food, and few families reported difficulties obtaining medicines or other necessities. Although no significant differences were found in the containment measures (e.g., staying at home, school closures, reduced work hours, or job loss), differences were found in the degree of exposure to COVID-19. The two items that remained significant even after applying the Bonferroni correction are those concerning whether a family member was exposed to someone with COVID-19 and whether a family member was hospitalized for COVID-19. No significant associations were found regarding exposure and the age at transplantation ($r = -.232, p = .112$) and years since the transplant ($r = -.093, p = .531$).

Impact

Regarding the impact experienced by families of both groups (see [Table 3](#)), caregivers reported on their own distress ($M = 5.21, SD = 2.64$) and that of their children's ($M = 4.77, SD = 2.12$). We highlight that 76% of all caregivers also perceived an increase in their anxiety levels and 71.9% a worsening in their mood. Adherence to health habits were also hindered, 64.6% of the respondents suffered from a poorer sleep quality

Table I. Participants Characteristics

	Total sample <i>n</i> = 96 N (%) or Mean ± SD	SOT group <i>n</i> = 48 N (%) or Mean ± SD	Control group <i>n</i> = 48 N (%) or Mean ± SD	X ² or <i>t</i>	<i>p</i>
Gender				.066	.798
Male	19 (19.8)	9 (18.8)	10 (20.8)		
Female	77 (80.2)	39 (81.3)	38 (79.2)		
Age	42.7 ± 8.2	42.4 ± 10.5	42.9 ± 5.1	.308	.759
Education				9.502	.051
Primary school	2 (2.1)	2 (4.2)	0 (0)		
Middle school	2 (2.1)	2 (4.2)	0 (0)		
High school	18 (18.7)	13 (27.1)	5 (10.4)		
College/university	62 (64.6)	26 (54.2)	36 (72.9)		
Postgraduate	12 (12.5)	5 (10.4)	7 (14.6)		
Relationship				.066	.798
Father	19 (19.8)	9 (18.8)	10 (20.8)		
Mother	77 (80.2)	39 (81.3)	38 (79.2)		
Number of children	1.8 ± 0.6	1.6 ± 0.6	1.8 ± 0.6	1.585	.089
Gender of pairing children				0	1
Male	50 (52.1)	25 (52.1)	25 (52.1)		
Female	46 (47.9)	23 (47.9)	23 (47.9)		
Age of pairing children	8.6 ± 4	8.6 ± 4	8.6 ± 4	0	1
Transplant type				—	—
Renal	17 (17.7)	17 (17.7)	—		
Hepatic	20 (20.8)	20 (20.8)	—		
Cardiac	10 (10.4)	10 (10.4)	—		
Pulmonary	1 (1)	1 (1)	—		
Age at the time of transplantation	4 ± 4	4 ± 4	—	—	—
Years from transplant	5 ± 3.8	5 ± 3.8	—	—	—

Note. SD = standard deviation;
SOT group = solid organ transplant group.

and 58.3% felt their physical health had worsened because of practicing less exercise. On the other hand, 59.4% of the respondents reported an improvement in the relationships among family members. Of the parents of a child with a diagnosis of a chronic illness, 75.7% reported feeling they were more capable of caring for them. No significant differences were found in terms of impact on the different items of the scale or its overall score. Also, a positive but low correlation between the total exposure score and the total impact score was found ($r = .259, p = .010$). No significant associations were observed in impact and the age at transplant ($r = .027, p = .857$) or years since the transplant ($r = -.064, p = .667$).

Qualitative Results
Personal Experience

A qualitative analysis of the results provided a clearer picture of the impact of COVID-19 on families and, specifically, on families of SOT recipients. Table 4 summarizes the themes extracted from the open-ended responses of the caregivers in the control group and the SOT group.

Families from SOT recipients and controls both described negative and positive aspects of the pandemic,

emphasizing negative aspects more than the positive ones.

On the positive side, families from both groups described spending more time with the family, enjoying being together and having a higher perception of family cohesion. Specifically, in the families of child and adolescent recipients of a transplant, they reported being used to health and safety measures related to COVID-19, so these did not represent an extra effort in their daily lives, and they also reported feeling more protected by the fact that society, in general, was taking more measures to reduce risk of infection. Many of the relatives believed the implantation and normalization of these measures helped them to reduce the stigma they have sometimes felt for wearing masks, having to maintain strict hand hygiene or undergoing isolation periods due to their child’s immunosuppression. In this group, parents reported some specific positive repercussions on health during the confinement, such as a decrease in the number of infections and an increase in their children’s weight.

On the negative side, all parents showed an increase in worries, fears, and sadness, with caregivers of transplant recipients specifically showing greater concern and fear about the risk of infecting their

Table II. Exposure to COVID-19 and Containment Measures in Families of SOT Recipients and Healthy Control Group

Items of the exposure scale	Total sample <i>n</i> = 96 N (%) or Mean ± SD	SOT group <i>n</i> = 48 N (%) or Mean ± SD	Control group <i>n</i> = 48 N (%) or Mean ± SD	X ² or <i>t</i>	<i>p</i>
Order to “stay at home”	89 (92.7)	45 (93.8)	44 (91.7)	.154	.695
Schools/child care centers were closed	96 (100)	48 (100)	48 (100)	NA	NA
Children education was disrupted	66 (72)	32 (66.7)	34 (70.8)	.194	.660
Unable to visit or care for a family member	72 (75)	33 (68.8)	39 (81.3)	2	.157
Family lived separately for health, safety or job demands	38 (39.6)	19 (39.6)	19 (39.6)	.000	1
Someone moved into our home	4 (4.2)	1 (2.1)	3 (6.3)	1.043	.307
We had to move out of home	6 (6.3)	5 (10.4)	1 (2.1)	2.84	.092
Someone in the family was working outside home	37 (38.5)	16 (33.3)	21 (43.8)	1.099	.294
Someone in the family was a healthcare provider	19 (19.8)	4 (8.3)	15 (31.3)	7.940	.005
Difficulties getting food	0 (0)	0 (0)	0 (0)	NA	NA
Difficulties getting medicine	1 (1)	0 (0)	1 (2.1)	1.011	.315
Difficulties getting health care when needed	10 (10.4)	3 (6.3)	7 (14.6)	1.780	.181
Difficulties getting other essentials	1 (1)	1 (2.1)	0 (0)	1.011	.315
Self-quarantined due to travel or possible exposure	20 (20.8)	11 (22.9)	9 (18.8)	.253	.615
Family income decreased	48 (50)	27 (56.3)	21 (43.8)	1.500	.221
Someone in the family had to cut back hours at work	49 (51)	25 (52.1)	24 (50)	.042	.838
Someone in the family was required to stop working	37 (38.5)	24 (50)	13 (27.1)	5.321	.021
Someone in the family lost its job permanently	4 (4.2)	2 (4.2)	2 (4.2)	.000	1
Health insurance was lost	1 (1)	0 (0)	1 (2.1)	1.011	.315
Important family events were missed or cancelled	63 (65.6)	29 (60.4)	34 (70.8)	1.154	.283
Someone in the family was exposed to someone with COVID-19	31 (32.3)	8 (16.7)	23 (47.9)	10.720	.001 ^a
Someone in the family had symptoms or was diagnosed with COVID-19	29 (30.2)	9 (18.8)	20 (41.7)	5.978	.014
Someone in the family was hospitalized for COVID-19	10 (10.4)	1 (2.1)	9 (18.8)	7.144	.008 ^a
Someone in the family was in the ICU for COVID-19	6 (6.3)	0 (0)	6 (12.5)	6.400	.011
Someone in the family died from COVID-19	7 (7.3)	1 (2.1)	6 (12.5)	3.852	.050
Exposure total score	7.75 ± 2.61	7.16 ± 1.9	8.33 ± 3.03	22.220	.029

Note. Percentages reflect affirmative answers to the items implying more exposure to COVID-19 pandemic.

NA, Chi-square test was considered not applicable when the value was considered a constant.

^aThe results are statistically significant after Bonferroni correction.

SD = standard deviation; SOT group = solid organ transplant group.

children. Moreover, both groups reported more sleep disturbances. They all highlighted the difficulty in reconciling family, child education, work, and domestic aspects. Both groups of parents expressed a significant sense of unspecified uncertainty as well, with significant concerns in the case of the relatives of the SOT group due to the possible impact of COVID-19 on the graft or in their child’s medical evolution.

As far as the children were concerned, parents perceived an increase in anxiety symptoms as well as an increase in the amount of time spent using technological devices. Some of the aspects that concerned parents, in general, were their children’s loss of social relationships and physical exercise habits.

Discussion

The COVID-19 pandemic represents an unprecedented cost at health, politics, economics, and social welfare levels ([The Lancet Public Health, 2020](#)). Likewise, the uncertainty, fears, sadness or anxiety

associated with the evolution of the pandemic have played and continue to play an important role in the emotional well-being of much of the population. Patients with chronic illness is one of the population groups that has been described as more vulnerable in the context of a health crisis such as the current one. In the context of uncertainty resulting from the evolution of the pandemic, it was foreseeable that families of patients with chronic diseases, especially of those that were immunosuppressed, were likely to experience the pandemic with a greater degree of emotional distress. There were many things about COVID-19 and patients with immunosuppressed status that were still unknown, including the psychological impact of COVID-19 on the families of pediatric SOT patients.

Our results show that families of pediatric transplant patients have been less exposed to COVID-19 than families of the control group. The former have practiced prevention measures for a longer period of time and have probably developed their own resources to deal with isolation, therefore protecting themselves more than the families of healthy children. Moreover,

Table III. Impact of COVID-19 and Containment Measures on Families of SOT Recipients and Healthy Control Group

Items of the impact scale	SOT group <i>n</i> = 48 Mean ± SD	Applicable items	Control group <i>n</i> = 48 Mean ± SD	Applicable items	<i>t</i>	<i>p</i>	<i>d</i> Cohen
Parenting	2.38 ± 0.96	39	2.47 ± 0.85	47	.42	.672	-.09
How family members get along with each other	2 ± 0.71	36	2 ± 0.65	38	0	1	0
Ability to care for child with an illness/condition	2.05 ± 0.66	37	2 ± 0	3	-.14	.89	.11
Ability to care for other children of the family	2.21 ± 0.97	19	2.57 ± 1.03	23	1.13	.264	-.36
Ability to care for older adults or people with disabilities in your family	2.69 ± 1.03	13	3.13 ± 1.01	23	1.24	.224	-.43
Physical wellbeing—exercise	2.91 ± 0.91	44	2.82 ± 0.99	44	-.45	.656	.09
Physical wellbeing—eating	2.5 ± 0.95	38	2.65 ± 0.87	46	.76	.448	-.16
Physical wellbeing—sleeping	2.91 ± 0.89	43	2.82 ± 0.86	45	-.45	.652	.10
Emotional wellbeing—anxiety	3.07 ± 0.75	45	2.98 ± 0.85	46	-.52	.602	.11
Emotional wellbeing—mood	2.93 ± 0.79	44	2.87 ± 0.78	45	-.39	.697	.08
Impact total score	2.55 ± 0.63		2.67 ± 0.62		.79	.432	-.19
Distress in parents	4.88 ± 2.59		5.54 ± 2.68		1.24	.219	-.25
Distress in children	4.69 ± 2.29		4.85 ± 1.94		.38	.702	-.07

Note. SD = standard deviation; SOT group = solid organ transplant group.

Applicable items: informs of the number of answers reported endorsed as applicable.

in our clinical practice, we have observed that some parents of pediatric transplant recipients have asked medical teams for documentation demonstrating their children's health status in order to limit their own exposure in their work environment. This extra effort to protect themselves is probably due to their fear, in some cases, of working in the medical field in the COVID-19 context (Menon et al., 2020) and, more specifically, to their fear of infecting their child, who they perceive as potentially more vulnerable than the general population (Cousino et al., 2020, Zhao et al., 2020).

The impact of COVID-19 on all families in both groups has been mostly negative (Orgilés et al., 2020), with an increase in the feelings of uncertainty, anxiety, and fear, and a worsening of health habits and routines. Not disregarding some minor but positive effects from the pandemic (Gambin et al., 2020) and in line with the psychosocial opportunities pointed out by Serlachius et al. (2020) regarding youth with chronic health conditions, most families in both groups reported that the pandemic has allowed them to spend and enjoy more time together and feel more united and cohesive as a family during the lockdown. A study by Cousino et al. (2020) found a significant psychological impact of COVID-19 in all family members of pediatric SOT recipients. In our study, we found similar results but, although a larger psychological impact was expected in the SOT group, no differences were found between the groups. Previously, Zhao et al. (2020) reported higher levels of anxiety and depression in caregivers of SOT recipients compared to the general population. Our results probably differ

because their comparison sample consisted of general population before the pandemic. Zgoura et al. (2020) found that life satisfaction in adults with a renal transplant diminished when comparing before and during the pandemic, but without any differences between transplant recipients and healthy controls. This lack of differences in impact can be explained in terms of already being familiar with preventive measures and having developed more coping strategies as part of their adaptation to chronic illness. For instance, the transplantation process involves important elements of stress, but at the same time, these families may be more accustomed to dealing with uncertainty, resulting in increased adaptability and more coping resources (Lupi et al., 2020). Moreover, pediatric transplant teams have provided specific support and advice to families during COVID-19, which could have mitigated the impact of the pandemic on SOT recipients' families.

Most families of pediatric transplant recipients reported that, as the entire population was required to go into lockdown and to follow specific prevention measures (use of masks, hand hygiene, social distance...) during the pandemic, they felt more protected than usual. Likewise, the common use of prevention measures by the population, which are everyday routine measures for patients who have received a SOT, made them feel more understood and decreased the perception of stigmatization toward their child. Occasionally, following emergencies such as the COVID-19 pandemic, people who have shared the experience, feel a greater sense of belonging and community support (Schellekens & van der Lee,

Table IV. Themes, definitions and example quotes extracted from the qualitative analysis.

Themes	Definition	Example quotes
Shared themes		
Family cohesion	Spending more time together as a family, sharing activities, dedicating more time to children and achieving a greater sense of unity.	<p>“We were able to spend more time at home and enjoy her [their daughter], which is something we were not able to do before”.—Mother of a 10-year-old female, SOT group.</p> <p>“Better relationships between our children, more time to help them do homework and becoming aware of their difficulties”.—Mother of a 12-year-old male, control group.</p>
Conciliation difficulties	Difficulties adapting to spending all the time together in the same place and reconciling work, kids’ schoolwork and household chores.	<p>“On numerous occasions, it was really overwhelming, the fact of having to work constantly together with the children’s classes and homework plus the household chores, everything was so chaotic”—Mother of a 16-year-old male, control group.</p> <p>“Difficulties caring for two little kids, trying to teach them as best as I could what they were doing in school and also working 100% from home”.—Mother of a 6-year-old male, control group.</p>
Social impact	Lack of in-person contact and sense of isolation from usual social and familiar networks, and the associated worries.	<p>“They [the children] lost every close relationship with their friends or teachers”.—Mother of a 7-year-old male, control group.</p> <p>“The loss of contact with other children was the worst part, she [their daughter] has compensated it with more time on the tablet”.—Mother of a 10-year-old female, control group.</p> <p>“The main problem was the impossibility to travel to our hometown to visit our other daughter”.—Father of a 5-year-old male, SOT group.</p>
Psychological impact	Worsening in the psychological well-being of any family members.	<p>“More apathy and nervousness”.—Mother of an 8-year-old male, control group.</p> <p>“We felt really tense and apprehensive at the beginning, we had some really difficult days with some anxiety crisis”.—Mother of 11-year-old male, SOT group.</p> <p>“The whole family had a very bad time, all of us experienced anxiety and a lot of depression”.—Mother of a 12-year-old female, SOT group.</p>
Uncertainty	Fear or worries about the future in a general or specific way (financial, work-related, academic or health concerns among others).	<p>“Fear for the future, my husband may lose his job”.—Mother of a 17-year-old female, control group.</p> <p>“Without doubt the most difficult part is the uncertainty of what is going to happen over the next months”.—Mother of a 17-year-old male, SOT group.</p>
Fear of infection	The specific fear that a member of the family might become infected.	<p>“The fear of the virus, of death, of going out and becoming infected”.—Mother of a 6-year-old male, control group.</p> <p>“Facing what is going to happen and knowing that we are all exposed to the infection is the worse part”.—Mother of a 17-year-old female, SOT group.</p>
Habits and activities	Change, reduction or increase of habits and activities as a response to the pandemic and its restrictions.	<p>“Less outdoor activities and less exercise”.—Mother of a 14-year-old female, SOT group.</p> <p>“The youngest one has developed an extreme attachment to technology devices”.—Mother of a 4-year-old male, control group.</p> <p>“Our routines were absolutely out of control”.—Mother of a 15-year-old male, control group.</p>

Table . (continued)

Themes	Definition	Example quotes
Specific themes		
Less stigmatization	Decreased sense of feeling different or having to take different actions from others in relation to the transplant process and associated aspects.	<p>“We experienced some relief when we saw that having to protect us from the virus or wearing a mask was not only about us”.—Mother of a 13-year-old male, SOT group.</p> <p>“The massive use of masks help transplanted people not to feel bad about wearing one, since they usually wear one”—Mother of an 8-year-old male, SOT group.</p>
Prevention Measures	Being already used to practicing prevention measures that are similar to those imposed during the pandemic and eased the adaptation to the pandemic and its restrictions.	<p>“For my daughter it was not that hard since we were used to being locked at home”.—Mother of an 8-year-old female, SOT group.</p> <p>“We managed the lockdown itself quite well because we have already been through it on two occasions. We built some routines and used our imagination to overcome boredom”.—Mother of a 10-year-old male, SOT group.</p>
Perception of child with SOT health improvement/safeness	Perceived improvements in their children’s health status that are directly linked to the pandemic and its restrictions.	<p>“Our daughter has not contracted any viruses, something that had never happened since her transplant, and this improved her health status a lot”.—Mother of a 10-year-old female, SOT group.</p> <p>“For our transplanted child it was better because he started gaining weight and we believe it’s because we started eating all meals at home. He has gained as much weight in three months as he had over the last four years”.—Father of an 11-year-old male, SOT group.</p> <p>“The hygiene measures for the society are really beneficial for transplanted people”.—Mother of an 8-year-old male, SOT group.</p>
Specific fear of infection	Represents an extra fear of infecting the transplanted children together with an explicit concern about their perceived greater vulnerability.	<p>“We suffered because of the fear of becoming infected and that our transplanted child could have severe complications”.—Mother of an 11-year-old male, SOT group.</p> <p>“My husband is on sick leave due to psychological issues because of how COVID-19 might affect our daughter”.—Mother of an 11-year-old male, SOT group.</p>

2020). The generalized use of prevention measures, as well as the fact of feeling more understood by society as a whole, could have produced a greater sense of belonging, which may have been a stress buffer for families of transplant recipients in the current healthcare crisis.

At a therapeutic level and with the aim of supporting the families of pediatric patients throughout the current crisis, it is important to develop remote interventions (Fong & Iarocci, 2020), in order to meet these families’ needs while reducing the risk of exposure to COVID-19, as well as to work on strategies to reduce the psychological impact both in transplant recipients and families in the general population. It seems that, for the families of pediatric SOT recipients, the perception of stigmatization and, therefore, the associated beliefs have a substantial impact on their experience of the disease. This aspect has been

overlooked in the context of the pandemic but it would probably be beneficial to introduce it in the therapeutic interventions with these families. Also, a promising strategy to implement with SOT families could be to reinforce their ability to be positive role models for other families who are going through a SOT process (e.g., expert patient programs) as well as for the general population in times of uncertainty (e.g., awareness campaigns). These families may be able to make important contributions when it comes to how to manage and adapt to uncertainty, especially in a health crisis like the current one.

While the current study is an important first step in understanding the impact of the pandemic on families of SOT pediatric recipients, there were some limitations. The sample size was limited by the previously established recruitment time, and response rates could have been improved by using more up-to-date

communication channels, reminders (Zhao et al., 2020) or incentives. Studies with SOT recipients tend to have similar samples to those in our study due to the specificity of the studied population (Cousino, et al., 2017). To contextualize the sample, the current number of SOT recipients under the age of 18 in our hospital is 268, and the incidence of pediatric SOT last year was 54 (OCATT, 2020). The sample recruited in our study correctly represents the higher prevalence of some types of transplants compared to others in our center. Regarding recruitment, we believe that the acquaintance control method was useful in the pandemic situation, although the control group may have been more familiar with prevention strategies than the general public because they were acquaintances of the SOT families. Also, some socio-demographic information about the sample (ethnicity, marital status, employment status, or education level of the child) was not registered. The instrument used was created ad hoc by the specialized Center for Pediatric Traumatic Stress at the outbreak of the pandemic because no other similar questionnaires were available. Additionally, it should be noted that the study did not include additional validated measures to evaluate quality of life, family functioning or coping strategies that could have provided a broader picture of the topic.

For future lines of research, we would recommend including other psychological instruments, for example, to assess depressive or anxious symptoms or coping strategies of caregivers, which could provide a broader view of the impact and resources of families of SOT recipients. In addition, the reported results reflect a precise moment in the pandemic; results may change over time as we get more knowledge about COVID-19 (Menon et al., 2020) or as new scenarios emerge (Downes et al., 2020). Results could also be expected to differ between countries or regions (Cousino et al., 2020), possibly due to differences in the mitigation measures taken, but more studies are needed. A next step for this line of research would be to conduct a follow-up evaluation on the impact, functioning, and coping strategies used by families of SOT recipients in the face of more sustained pandemic-related stress. In general, further longitudinal research on the impact of the COVID-19 pandemic on families of chronically ill children is needed.

In conclusion, while coping with the pandemic and its effects has been a huge challenge for the entire population, families with SOT patients were observed to be able to protect themselves more from the virus probably due to their prior knowledge about, and practice of, the safety measures and to their increased sense of vulnerability and precaution. Also, although the emotional impact has generally been negative, the families of transplant recipients have benefited from

the use of preventive measures by the entire population and from the fact that they and their children have felt more understood, which has diminished feelings and perceptions of stigmatization associated with pediatric transplantation.

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Conflicts of interest:

J.A.R.Q was on the speakers' bureau and/or acted as consultant for Eli-Lilly, Janssen-Cilag, Novartis, Shire, Takeda, Bial, Shionogui, Lundbeck, Almirall, Braingaze, Sincrolab, Medice and Rubió, Raffo in the last 5 years. He also received travel awards (air tickets + hotel) for taking part in psychiatric meetings from Janssen-Cilag, Rubió, Shire, Takeda, Shionogui, Bial, Medice and Eli-Lilly. The Department of Psychiatry chaired by him received unrestricted educational and research support from the following companies in the last 5 years: Eli-Lilly, Lundbeck, Janssen-Cilag, Actelion, Shire, Ferrer, Oryzon, Roche, Psious, and Rubió.

The rest of the authors have no conflicts of interest to declare.

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