




BRIEF COMMUNICATION

Awareness and concerns about novel coronavirus disease 2019 (COVID-19) among parents of pediatric liver transplant recipients

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Abstract

Objectives: Pediatric transplant recipients may be at increased risk of developing serious infections due to COVID-19. We undertook a web-based survey among parents of post-liver transplant pediatric patients to assess knowledge and concerns regarding COVID-19 pandemic and impact of social media on them.

Methods: This cross-sectional online survey was conducted between March 21 and March 26, 2020. A 19-item questionnaire was sent to 172 parents of post-liver transplant children.

Results: 106 (62%) of parents responded. Median time since transplant was 31 (12–52) months. The majority of parents had good understanding regarding symptomatology and routes of transmission. Only 27% were aware of feco-oral transmission, and 34% knew about gastrointestinal symptoms of COVID-19. 100% of parents understood concept of social distancing, and 70% knew that asymptomatic individuals can transmit the virus. Television followed by newspapers was the main source of their information, though over 40% claim to regularly receive information through social media. 87% would consult their doctor if the child had flu-like symptoms rather than modify immunosuppression or try alternative medications. Parental concerns mainly revolved around early recognition of symptoms, queries on unconventional treatments circulating over social media, and supply of medications during the lock-down period.

Conclusions: The majority of parents had basic understanding of COVID-19 pandemic. Social media appeared to be an important source of information. Results from this survey helped us in modifying patient care protocols to ensure continuity of care while maintaining social distancing.

KEYWORDS

coronavirus disease 2019, pediatric liver transplantation, questionnaire, social distancing, social media

1 | INTRODUCTION

The nCoV-2 responsible for causing the COVID-19 pandemic has created worldwide chaos and panic.¹ The most severe spectrum of this pandemic is being seen in the elderly and in adults with comorbidities.² In the largest cohort of patients from China, children and adolescents comprised less than 2% of the affected patients with no mortality recorded in children younger than 9 years of age.³ Since nCoV-2 does not have an established therapy currently and there is not a vaccine available for prevention, the only way to control its spread is by avoiding contact with infected persons.^{4,5} This concept of social distancing, in which individuals have to maintain at least one meter distance from each other, is being widely publicized by the WHO, CDC, and ICMR for preventing spread of the virus.

While there are only a handful of case reports to date regarding COVID-19 infection in post-transplant patients, any infection in this cohort including COVID-19 is a major concern because of their immunocompromised status. Pediatric liver transplant recipients form a special group due to their continued association with their treating teams as these patients require periodic follow-up for clinical evaluation and also for investigations including liver functions, immunosuppression levels, and abdominal imaging. There is evidence that the responsibility of caring for these children also increases stress levels in the family leading to increased levels of anxiety in their carers.⁶ Clear guidance and reassurance is necessary for these families during this period. A questionnaire-based study was conducted to assess the level of awareness among parents of pediatric liver transplant recipients and also identify their main areas of concerns so that effective and targeted education can be provided.

2 | MATERIALS AND METHODS

The study was conducted at Dr Rela Institute and Medical Centre, which is a large volume quaternary liver transplant hospital. A cross-sectional online survey was sent to the primary caregivers of 172 pediatric liver transplant recipients whom we had transplanted in the last 5 years. In total, 230 children were transplanted in our center over the last 5 years, of which 58 were excluded from the survey, as these children were being followed up by the pediatric hepatologist in their own native places and we could not contact them. The survey was conducted between the dates March 21, 2020, and March 26, 2020. The 19-point questionnaire was distributed through the "Google Forms" online software through email, and a reminder email was sent after 72 hours. The questionnaire was designed based on queries that we received from a cross-section of our patient carers following initial reports of cases of COVID-19 in India and the WHO declaration of it as a pandemic (Table 1). Queries were structured under the following headings:

TABLE 1 Awareness of COVID-19 among parents of pediatric liver transplant recipients (n = 106)

Questions	No. of Responses (%)
What are the main symptoms of Coronavirus infection (COVID-19)?	
Fever	100 (94)
Breathlessness	91 (86)
Dry cough	95 (90)
Wheezing	30 (28)
Running nose	48 (45)
Diarrhea	36 (34)
Can an adult or child without any symptoms of the infection transmit the virus?	
Never	13 (12)
Quite possible as they might be in the incubation period before onset of symptoms	74 (70)
Not sure	19 (18)
What are the modes of transmission of infection in COVID-19?	
Direct (Droplet) infection by coughing/sneezing	99 (94)
Touching surfaces contaminated with respiratory secretions	100 (94)
Kissing the baby	78 (74)
Through the food you eat	29 (27)
Which is the best means available at present to prevent COVID-19 infection?	
Vaccination	1 (1)
Antibiotic prophylaxis	1 (1)
Avoid contact with other people and gatherings (social distancing)	104 (98)
What is the impact of Coronavirus infection (COVID-19) on your child?	
It has no effect on my child	3 (3)
It affects children but not concerned as it is usually asymptomatic in children	12 (11)
Concerned as my child is receiving immunosuppressive medications	91 (86)
What are the precautions you are currently taking for your child in view of the COVID-19 situation?	
Keep the child isolated in a room	13 (12)
Keeping the child at home and minimizing contact with visitors	93 (88)
Allowing him to play with friends in the park, but with a mask	0 (0)
No restrictions	0 (0)
How will you disinfect your child's hand if he/she had been in contact with the possible contaminated surfaces? (Multiple responses)	
Wash with running water	2 (2)
Using soap and water for at least 20 s	53 (50)

(Continues)

TABLE 1 (Continued)

Questions	No. of Responses (%)
Alcohol based hand rub	21 (20)
All are equally effective	30 (28)
What will you do when your child has symptoms of flu such as fever, cough or running nose?	
Treat with home remedies which have been effective before	6 (6)
Will contact my doctor or the transplant unit for advice	92 (87)
Will start a course of antibiotics which was previously given for a similar infection	1 (1)
All of the above	7 (6)
What will you do with the immunosuppressant medications if you have flu like symptoms?	
Will stop the medications upfront as there is infection	0 (0)
Will skip a few doses and restart when the child is fine	2 (2)
Will consult transplant centre for advice	104 (98)
Do you think routine blood tests (liver function test, immunosuppression levels) need to be deferred as there is a risk of contact with someone infected with COVID-19?	
No, we don't feel there is a risk and routine tests can be done	10 (10)
There is a definite risk and I want to defer the labs	11 (10)
There is a risk, so will contact the transplant centre for advice	85 (80)
Do you know which medicines are to be avoided in children with respiratory symptoms in the current scenario? (Multiple responses)	
Paracetamol	16 (15)
Pain killers such as Ibuprofen, diclofenac, aspirin	69 (65)
Antibiotics	26 (25)
Immunity suppressing medications (does not include routine medication associated with liver transplant)	50 (47)
Did your child have a respiratory illness in the last 4 wk which worried you because of the current COVID-19 problem?	
Yes	7 (7)
No	99 (93)
Which medium do you commonly depend on for getting information regarding COVID-19 problem?	
Television	90 (85)
WhatsApp	54 (51)
Facebook	34 (32)
Newspaper	58 (55)
Books	8 (8)
Direct discussion with a doctor	42 (40)
Others (if any)	9 (8)

(Continues)

TABLE 1 (Continued)

Questions	No. of Responses (%)
Which medium do you commonly depend on for getting information regarding safety precautions to preventing COVID-19 infection in your child? (multiple responses)	
Television	74 (70)
WhatsApp	47 (44)
Facebook	28 (26)
Newspaper	48 (45)
Books	8 (7)
Direct discussion with a doctor	49 (46)
Others (if any)	10 (9)
Please list up to five questions regarding the care of your child in the current COVID-19 scenario which you believe are important	72 (68)

2.1 | Awareness of COVID-19 epidemiology

Parents were asked about the symptomatology of COVID-19, its modes of transmission, the possibility of an asymptomatic person infecting others, and also impact on COVID-19 on their child who is a liver recipient.

2.2 | Preventive and protective measures against infection

Parents were asked about the current available means for preventing COVID-19, any precautions they would take to minimize the contact of their child with others individuals, and the methods they would use for disinfection in case of contact with a contaminated surface. We also wanted to know how they would act if their child develops any symptoms of flu, if they are worried on that and what they would do with the administration of immunosuppressive medications in such a scenario. We also elicited their awareness on the class of medicines to be avoided (like NSAIDs) in case of a flu and also their thoughts on deferring the routine clinical and/or laboratory visits as these children can have potential exposure at these places.

2.3 | Sources of information regarding COVID-19

We wanted to know the commonest sources the parents would depend upon for getting general information on COVID-19 and also on the sources they would rely on for information regarding precautions and preventive measures to be followed during the ongoing pandemic.

2.4 | Areas of concerns related to the pandemic

We asked the parents of pediatric liver transplant recipients to list up to five concerns that they wished the medical team to clarify

regarding COVID-19, and they were classified into general queries, information on COVID-19 which are yet to have scientific basis, concerns regarding prevention and cure, concerns due to lack of access and lockdown, and others.

Data were collected and tabulated in an Excel spreadsheet. Data were expressed as frequencies and proportions. The parental response was considered as the consent for participation in the study.

3 | RESULTS

There were 106 responses among 172 carers (62% response rate). There were no incomplete submissions. The median post-transplant duration of the recipients was 31 (12-52) months. The responses were categorized under the following headings (Table 1).

3.1 | Awareness of COVID-19 epidemiology

Most parents had a good awareness of the symptoms of COVID-19. A majority recognized fever and its respiratory symptomatology (fever—94%, cough—90%, and breathlessness—86%). Only 34% of parents knew that diarrhea is a common symptom in COVID-19 infection. 70% of the parents were aware that asymptomatic individuals including children can spread the infection. 18% of the caregivers were not sure whether asymptomatic individuals can transmit the virus, and 12% felt asymptomatic individuals can never spread infection. Parents were aware of the main modes of disease transmission including droplet spread through coughing or sneezing (93%), and fomites (94%). 74% were also aware that virus is potentially transmissible by kissing. Only 27% were aware that feco-oral transmission is possible. 86% also felt that COVID-19 infection can be severe in the post-liver transplant patients, as they are immunocompromised.

3.2 | Preventive and protective measures against infection

11% of parents were not concerned of the COVID-19, and 3% felt it never affects children. Almost all respondents (98%) recognized the importance of social distancing in preventing COVID-19 infection. 88% wanted to keep the child strictly at home and avoid visitors. 12% would isolate their child in a room. None of the parents would allow the child to go out and play with his/her friends, or would take them to dine out, movies, or play stores (without any restrictions). 70% were aware that either washing with soap water or with alcohol rub can disinfect the contaminated hands.

87% would contact the child specialist or the transplant unit if their child displayed flu-like symptoms. Within the last four weeks, 7(7%) children had some respiratory problem which worried the parents due to the ongoing pandemic. 98% would never modify their immunosuppressive agents including stopping or reducing the dose if there is a flu-like illness in their child and

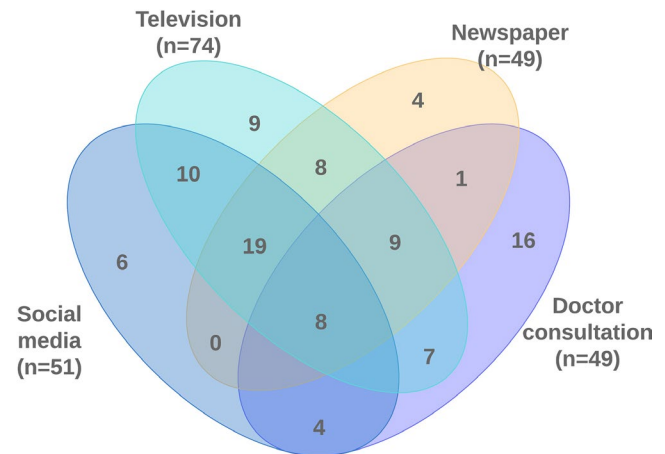


FIGURE 1 Venn diagram showing the various sources of information that parents relied upon for getting information on COVID-19

would rather talk to the transplant team for advice. Majority (65%) would also avoid non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen, aspirin, and diclofenac (8). 80% of responding parents understood the risk of traveling outside including for clinic appointments and blood tests and would contact the transplant team for guidance. 10% respondents were not worried about visiting the hospital, and 10% wanted to defer the visit or blood test because of the risk of infection.

3.3 | Sources of information regarding COVID-19

85% of respondents depended on television, and 55% depended on newspapers to get information regarding the pandemic and safety precautions to be observed (Figure 1). Interestingly, social media such as WhatsApp and Facebook appeared to be an important source of COVID-19-related information among the respondents with over 40% stating they would rely on these sources for advice about safety measures.

3.4 | Areas of concerns related to the pandemic

68% of respondents conveyed their concerns through the questionnaire (Table 2). The queries were primarily concerned about early recognition of symptoms, questions related to home remedies and unconventional treatments circulating over social media and concerns regarding treatment options, follow-up visits, and supply of medications during the period of lockdown.

4 | DISCUSSION

Since COVID-19 was declared as a pandemic by the WHO, over 850 000 individuals have been affected by the virus.⁴ To date, there

TABLE 2 List of common concerns raised by carers of pediatric liver transplant recipients regarding the COVID-19 pandemic**General queries regarding COVID-19:**

- Common symptoms of COVID-19
- How to differentiate from other flu like illness
- Duration of isolation if someone is infected
- Any precautions the donor needs to take
- Is the outcome different in my child who is immune suppressed
- Does asthma affect the outcome in my child

Possible information on COVID-19 which is yet to have definite scientific basis:

- Special diet/ immune booster diet to prevent COVID-19 to my child
- Role of vitamin C or fruits rich in vitamin C to prevent COVID-19
- Can Valganciclovir or antibiotics protect my baby from COVID-19⁴
- Drinking hot water and elimination of the virus

Concerns regarding prevention and cure:

- Should we make our children wear masks even at home
- Parents working in the medical field and need of self-isolation from their child
- Food items to be avoided
- Benefits of home remedy
- Decreasing or stop immunosuppressants like tacrolimus if there are flu symptoms

Concerns due to lack of access and lockdown:

- Procuring medications for the child as there is lockdown
- Postponing the routine blood tests of my child in view of current scenario of COVID-19
- Hotline number of the institute to contact in emergency

Other concerns:

- Studies available on effect of COVID-19 on liver transplant recipients
- Vaccinations against COVID-19
- Visiting a general paediatrician for the child's health concerns

are only a few case reports of COVID-19 infection in solid organ transplant recipients.^{7,8} In a previous review on the effect of common respiratory virus in recipients of solid organ transplantation, it was reported that transplant recipients were more prone to develop lower respiratory tract infection which can progress more rapidly when compared to the normal population. These patients also have higher viral loads, prolonged shedding of the viruses, and increased morbidity and mortality from respiratory failure.⁹ It is also known that the corona group of viruses can themselves worsen the outcome in transplant recipients.^{10,11} Hence, the impact of the COVID-19 pandemic on the health of transplant recipients cannot be under-estimated.

Another factor of significance is the explosion of information on social media platforms which is creating a "pandemic of panic."¹² In a recent study looking at the awareness of general public on COVID-19 done across the USA and UK, a number of misconceptions regarding this viral infection and the increasing ability of social media to influence beliefs were identified.¹³ The WHO has also identified this as a major safety concern and published a "myth-buster" list related to the COVID-19 pandemic.¹⁴ We conducted this survey to assess the extent of awareness among carers of our pediatric recipients as we expected them to be concerned.

More than the general population. It was also a concern that excessive reliance on social media could lead to them making health-care decisions and interventions which may be unsafe for the child and the graft.

The results of our study are encouraging and suggest that the parents are quite clued in regarding the current COVID-19 scenario. Majority were aware of the symptomatology and mode of spread of infection, and most recognized the increased risk for their child due to the immunosuppression. 30% of the parents were either not sure or were unaware about the fact that asymptomatic carriers can transmit the infection.

It was also reassuring that parents were more likely to get their information from traditional media such as television and newspaper which are considered more trustworthy and less likely to provide unsubstantiated information. However, nearly 40% of respondents said that they received information and even health-related advice from social media which is a matter of concern.¹⁵

Almost all respondents understood the need and significance of social distancing and were practising it consistent with current guidance. 12% of parents however went to the extreme of suggesting the need for strict isolation to a room. We feel that once we minimize the number of home visitors and the basics of hygiene are practised, isolation is not needed unless the child shows some symptoms of flu. Such isolation is a definite stressor for a child and can lead to mental problems like anxiety and post-traumatic stress disorder.¹⁶ In children of appropriate mental age, it is recommended that parents discuss the seriousness of the current scenario in simple terms and should not induce panic.

Majority of the respondents appeared to have a healthy belief in the healthcare system and would contact the medical team in case of any worrying signs. 98% of the participants responded that they will not alter the immunosuppression without discussing with the primary physician. They also understood the need for minimizing exposure for the child on clinic appointments and were happy to interact with the medical team on the phone.

From this survey, we have used inputs from the parental responses along with the most common queries they had to modify our patient care protocols during this period and a detailed parent-friendly information brochure on COVID-19 was prepared and circulated through emails to the parents of liver transplant recipients. We created a dedicated helpline number and video consultation facilities for easy access of the parents to get in touch with us. We also have initiated home visits for routine blood sample collection to minimize hospital visit. As the knowledge regarding COVID-19 continues to increase exponentially, we have tried to provide the most updated information to the parents of our pediatric liver transplant recipients and also rectified any misinformation they had through the abovementioned services.

We had a response rate of 62% which is appreciable for an online survey. Our medium for long-term contact with the patient's family is usually through emails, and we had conducted this survey through emails. Also, we have a strong communication and commitment that exists between the parent and the transplant team. These factors probably helped in getting a good response to this survey.

The main limitations of the study are that it is a single-center study and the questionnaire used is specific for COVID-19 and hence by its very nature not validated. It is also possible that the concerns regarding the influence of social media may not be constant across all countries or societies. However, we believe that the results of the survey can guide pediatric liver transplant teams across the globe in addressing common concerns of parents and ensuring that they get accurate and reliable information.

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CONFLICTS OF INTEREST

None declared.

AUTHOR CONTRIBUTIONS

Jagadeesh Menon and Naresh Shanmugam, and Mettu Srinivas Reddy: Prepared the questionnaire; Jagadeesh Menon and Naresh Shanmugam: Collected and compiled the data; Jagadeesh Menon and Naresh Shanmugam: Prepared the manuscript; Kinisha Patel: Assisted in collecting the data; Abdul Hakeem and Mettu Srinivas Reddy: Did the proofreading; Mettu Srinivas Reddy: Proposed the topic; and Mohamed Rela: Did the final proofreading and gave the approval for publishing the manuscript.

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