



Challenges in accessing medical care among post-transplant recipients during covid 19 pandemic: a questionnaire-based study

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Abstract

BACKGROUND

Organ transplant recipients require long term follow up, laboratory investigation, particularly immunosuppressive trough levels. They are advised to follow a healthy diet and regular physical activity. Covid 19 pandemic has become an obstacle for this. This study attempts to analyse the challenges faced in accessing medical care in post-transplant recipients during the pandemic and identify the problems arising in following proper diet and physical activity.

METHODS

A cross sectional study was conducted among post-transplant recipients who are undergoing follow up at AIMS Kochi after institution ethics committee approval. A self-prepared questionnaire assessing the challenges faced in accessing medical care during this pandemic was used and the responses were recorded via telephone and google forms.

RESULTS

There were 303 respondents with median age was 51 years. 33.7% reported difficulty in getting medicines, mainly due to lack of drug availability (15.5%), financial problems and lack of help. 5.9% skipped their medications. Difficulty in accessing routine laboratory investigation was reported by 35.6% and in accessing transplant centre by 53.8%. 30.4% skipped the routine laboratory investigation and 44.2% skipped their visit to transplantation centre. Major challenge being the fear of getting out due to the scare of transmitting covid 19. Lack of access to telehealth facilities was also found. Daily physical activity was found to be decreased.

CONCLUSION

Post-transplant recipients being vulnerable section of our society due to their immunosuppressed state, hence important to find out the challenges faced by them in accessing medical care and develop strategies to mitigate them.

Keywords: Challenges, Covid pandemic, Laboratory services, medical care, post-transplant recipients, Telemedicine

INTRODUCTION

The Global pandemic of SARS coronavirus 2 which causes covid-19 has become a global threat and major healthcare concern[1].In addition to the clinical therapies conducted the countries are focusing on social distancing and lockdown ,to minimize the disease spread [2] .Thus covid-19 pandemic has brought unprecedented medical, economical and physiological crisis [3]to all especially to the most vulnerable group of the society like post-transplant recipient .Post transplant recipients require long-term follow-up with regular lab investigation, strictly followed intake of immunosuppressive drugs and in addition should maintain healthy lifestyle with regular physical activity[2].Since maintaining health and seeking proper medical care is even more important after transplantation and the emergence of covid pandemic and lockdown has impacted adversely, it is important in understanding patient concern and challenges faced by them during the present situation of covid 19 pandemic[4]. To date several studies have reported potential risk of acquiring covid 19 and the challenges in performing transplantation during this pandemic. Maintaining their health and seeking proper medical care is even more important after an organ transplant. But there are very few studies in India that have taken into account, the real challenges faced by post-transplant recipients in accessing medical care during covid 19 pandemic. This study attempts to find out the challenges faced by them in accessing medical care during this period and to identify the problems faced by them in following proper diet and physical activity which is of at most importance in their daily health care.

MATERIALS AND METHODS

A cross-sectional study undertaken between September –December 2020 among post transplants, who had their surgery done during 2006 to 2019 period and having their follow-up at AIMS Kochi .The study was initiated following approval from the institutional ethics committee of Aims Kochi.A form of a self-prepared questionnaire which was reviewed by five experts, containing 35 questions, 9questions on socio demographic details and remaining 26 questions assessing challenges in accessing medical care among post-transplant recipients during the covid pandemic was made.Then,A pilot study was conducted among 40 post-transplant recipients undergoing follow up at AIMS Kochi using this questionnaire and among them 23 responded. The results was then analyzed and then sample size was calculated. Based on the proportion of challenges such as difficulty in getting medicine (39.13%), difficulty in accessing transplant center (60.8%), difficulty to carryout routine laboratory investigations (47.83%) during COVID-19 pandemic observed from the results of the pilot study conducted in 23 post-transplant recipients and with 20% relative precision and 95% confidence, the minimum sample size comes to 149, 62 and 105.Then the minimum sample size for the study was 149.Contact details of the post-transplant recipients undergoing follow up was collected from the hospital after signing Non-disclosure agreement form. Each patient was contacted directly via telephone and the survey process, their concerns and confidentiality of the responses was explained. Then their responses to the questionnaire was recorded after obtaining their consent. Out of 600 contacted 301 responses were obtained. The data were tabulated in Excel sheet and percentage prevalence rate of challenges in accessing medical care among post-transplant recipients during the covid pandemic with 95% confidence interval was computed.

RESULT

Total number of people contacted	600
Total responded(n)	303

SEX	
Male	254
Female	49
AGE	
Less than or equal to 50 years	147
More than 50 years	156
ECONOMIC STATUS	
Above Poverty line	242
Below Poverty line	61
DURATION	
Within 4 years	194
More than 4 years	109
DISTRICT	
From Ernakulam	50
Outside Ernakulam	253

We conducted a short survey amongst liver transplant recipients to assess the impact and challenges faced during COVID-19 lockdown.

Median age was 51 and the male:female was 5:1 and the median of year after transplantation was 4. From the survey it was noted that 79.9% of the patients are above the poverty line and 20.1% of the patients are below the poverty line.

Table 1: Distribution of challenges faced by post-transplant recipients in accessing medical care

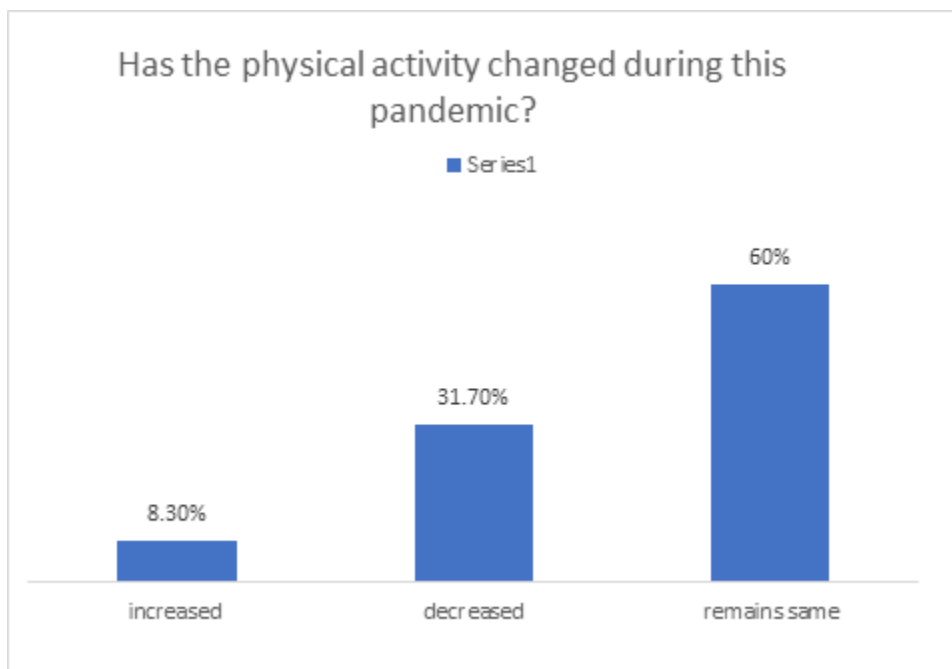
	challenges in accessing medication	challenges in accessing laboratory investigations	challenges in accessing transplant centres																														
Access	<p>Bar chart showing challenges in accessing medication. The x-axis has two categories: 'Before pandemic' and 'During Pandemic'. The y-axis represents percentage. The bar for 'Before pandemic' is at 6.9, and the bar for 'During Pandemic' is at 33.7.</p>	<p>Bar chart showing challenges in accessing laboratory investigations. The x-axis has two categories: 'Before pandemic' and 'During Pandemic'. The y-axis represents percentage. The bar for 'Before pandemic' is at 3.6, and the bar for 'During Pandemic' is at 35.6.</p>	<p>Bar chart showing challenges in accessing transplant centres. The x-axis has one category: 'During Pandemic'. The y-axis represents percentage. The bar is at 33.8.</p>																														
Challenges	<table border="1"> <tr> <td>I could not get following drugs</td> <td>15.5%</td> </tr> <tr> <td>I have no money</td> <td>21.1%</td> </tr> <tr> <td>Have nobody to help</td> <td>3.6%</td> </tr> <tr> <td>Others</td> <td>8.6%</td> </tr> </table>	I could not get following drugs	15.5%	I have no money	21.1%	Have nobody to help	3.6%	Others	8.6%	<table border="1"> <tr> <td>unable to go out as there is no transport facility</td> <td>17.2%</td> </tr> <tr> <td>no Laboratories nearby</td> <td>2.3%</td> </tr> <tr> <td>Have no money</td> <td>13.9%</td> </tr> <tr> <td>have nobody to help</td> <td>3%</td> </tr> <tr> <td>scared to go out</td> <td>17.2%</td> </tr> <tr> <td>others</td> <td>7.9%</td> </tr> </table>	unable to go out as there is no transport facility	17.2%	no Laboratories nearby	2.3%	Have no money	13.9%	have nobody to help	3%	scared to go out	17.2%	others	7.9%	<table border="1"> <tr> <td>Unable to go out as there is no transport facility</td> <td>27.7%</td> </tr> <tr> <td>Have no money</td> <td>15.5%</td> </tr> <tr> <td>Have nobody to help</td> <td>0.7%</td> </tr> <tr> <td>Scared to go out</td> <td>25.7%</td> </tr> <tr> <td>Others</td> <td>9.2%</td> </tr> </table>	Unable to go out as there is no transport facility	27.7%	Have no money	15.5%	Have nobody to help	0.7%	Scared to go out	25.7%	Others	9.2%
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Skipped or not due to the challenge	<p>Didn't skip medications: 94%</p> <p>Skipped medications: 6%</p>	<p>Didnt skip routine laboratory investigations: 69.6%</p> <p>Skipped routitine laboratory investigations: 30.4%</p>	<p>Didn't skip routine transplant centre visit :55.8%</p> <p>Skipped routine transplant centre visit :44.2%</p>																														

Only 48.5% were aware of the telemedicine facility from which only 30.4% had access to it.

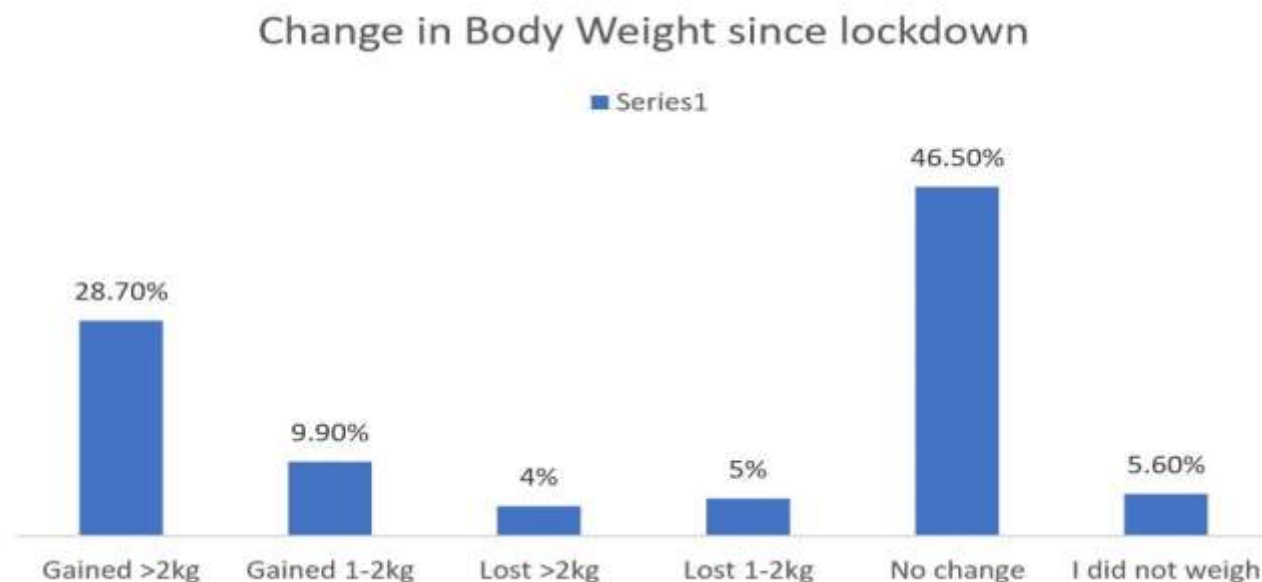
Table 2: Distribution of reasons for lack of access to telemedicine facilities

Don't know	42.9%
Don't have computer	1%
Don't have internet	1%
Don't have any need	15.2%
Preferred face to face consultation	16.5%
Was worried about mistakes in medications over internet	2%

Figure 1: Bar diagram showing percentage prevalence of change in physical activity during pandemic



The physical activity data is shown like this because 20.5% are scared of covid, 3% no space at home ,4% had a disease 9.6% had other reasons.

Figure 2 : Bar diagram showing percentage prevalence of change in body weight since lockdown

Only 2.3% have been covid positive but still 33.3% of them isolate themselves in scare of the pandemic. 67% has not been directly or indirectly affected by the pandemic but 17.5% have been affected psychologically, 3.6% affected physically and 7.3% have been affected both physically and psychologically and 5.3% by other reasons.

DISCUSSION

This survey clearly demonstrates the various confounding effects of COVID-19 pandemic on the medical care of liver transplant recipients. Individuals who are beneficiaries of an organ transplant must take immunosuppressive medications, prophylactic antimicrobials and follow healthy lifestyle. They also require regular clinical checkup to detect any signs of immunological injury, adverse effect of drugs or recurrence of disease lifelong. To contain the spread of COVID-19 the government had mandated absolute lockdown which affected their life adversely [2]. The purpose of this study was to determine the challenges faced by transplant recipients in accessing medicines, laboratory services, routine visit to doctor, telemedicine facilities along with the problems faced by them in following healthy lifestyle during COVID 19 pandemic.

Our short survey found that there was an increased difficulty in accessing medications during the pandemic (33.7%) than before (6.9%). Even though there are governmental (KARUNYA, ECHS / CGHS)

and few nongovernmental organization providing medicines at a subsidy; 13.2% were not aware of it. Moreover, from the remaining 86.8% who were aware and beneficiaries (50.2%) a majority had difficulty getting access to the same. The major challenge being the economic crisis (21.1%).

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During this period lack of availability of the immunosuppressive drugs mainly Tacrolimus was a major concern. Doorstep delivery of drugs was also affected. Other problems noted were lack of help to purchase drugs and transportation. Due to the above mentioned reasons 5.9% skipped their prescribed medicines. Surprisingly, many intentionally avoided their medications in the fear of the effects of immunosuppression during this pandemic. According to the guidelines of liver transplant society of India (ITSI), although there is a concern that organ transplant patients may be at a higher risk of COVID-19 infection, there is no evidence as of now to modify the immunosuppressive protocol. Standard immunosuppressive therapy must be continued in the post-transplant period till further data is available [7]

There was a tenfold increase (35.6%) in difficulty to carry out routine laboratory investigations during COVID-19 as compared to before and more than half of participants reported difficulty in visiting doctor mainly due to the lack of transport facilities and scare of getting out in fear of COVID 19.

Most transplant centres have limited slot availability for the patients to obviate physical interaction of patients with others and also the health workers. [6]

Financial problems, lack of help, lack of laboratories nearby were few other problems reported .Due to the above reasons about 44.2% skipped their routine visit to transplant centre and very few preferred visiting nearby hospitals for future follow-up since going out increases their chance of getting infected with covid19.

The relevance of the study by Dinesh Jyothimani et al were supported by these findings.[2]

It is usual tendency for majority of them do their laboratory investigation along with transplant follow up visit and following covid-19 prohibitory advisories, there was an increasing trend to skip both laboratory test and follow up visits. CDC guidelines recommends to increase the utilisation of telemedicine service to fill the void created by covid-19 and maintain the patient contact still during social distancing.[3] Even though they recommend using telemedicine during this time we found in our survey that 51.5% are not aware of the facility and out of those who know about this ,30.4% are not using these facilities. This was found to be because of several limitations like lack of internet, lack of device, they felt there was no need, they preferred face to face consultation distancing [3] among which lack of knowledge about it was the major concern. Although this can maintain social distancing, physical examination via virtual visit and significant finding can be missed and can bring unintended complications. Due to all these reasons, only 7.6% of the respondents are planning to use telemedicine facilities if COVID regulations continue unlike the finding by Abdul R Hakeem et al where majority of the respondents liked the idea of teleconsultation which reveals that lack of awareness might be the reason among our study population.[4]

Recent studies shows that weight gain is a common issue faced by post-transplant recipients during this pandemic [2][4] while maintaining a healthy weight is

far more important for them. [5]. Potential causes for weight gain after a transplant includes use of immunosuppressants, lack of physical activity and dietary changes [5].38.6% reported an increase in body weight since lockdown.31.7% reported a decrease in physical activity reasons being scare of going out due to COVID-19, having a disease, lack of space, supporting the findings by Dinesh Jyothimani et al[2] whereas it is to note that 95.7% follows proper diet. Diabetes mellitus and other comorbidities was found to be one of reasons behind not following proper diet.

Regarding the psychological aspect few(17.5 %)were affected by lockdown. This is mainly because of the fear of covid-19 as they are immunologically weak, other reason is being lonely and 7.3% were affected both psychologically and physically

Overall this study strengthens the idea of increasing awareness regarding telemedicine, making facilities like Karunya, ECHS, CGHS accessible to the beneficiaries, providing emotional support and other strategies as [3] mentioned cost mitigation strategies and stock piling of medicines to reduce their difficulties

The most obvious finding to come out from our study is that in any emergency situation like covid-19 post-transplant recipients being the vulnerable group of our society are affected adversely especially in accessing their routine proper medical care. As transplantation is a lifelong contract between the patient and the clinician [4], their post-transplant health is also vital for them, still there are very few studies centralising this. Thus, we concentrate this facet of transplant patients about challenges in accessing medical care among them during covid-19 pandemic.

The major strength of our study is that it can be applicable to the similar emergency situation in future as post transplantation care is a lifelong support policy.

Considering the progressive nature and uncertainty regarding the future concern of covid-19, it is extremely important for the transplant patients to prepare to the situation for preventing dangerous consequences.

Our study was limited to single Centre, focusing on small population under treatment in Kerala. Due to certain constraints our study was done quantitatively, but it would be more informative if done qualitatively

CONCLUSION

Cost mitigation strategies and stockpiling of medicines and increasing awareness about telemedicine can serve as a method to eradicate these challenges. Even though our study only deals with the medical care aspects, there are furthermore challenges to be targeted with recognition to the post-transplant care during an emergency situation like covid-19.

Our study was a single centric study focusing on a small population under treatment in a specific centre of Kerala.

Due to certain constrains our study our study was done quantitatively, but it would be more informative if done qualitatively.

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