

BRIEF COMMUNICATION

When immunosuppression and COVID-19 intersect: An exploratory qualitative study of young lung transplant recipient perceptions of daily life during a pandemic

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Abstract

Background: The COVID-19 pandemic poses an increased risk of infection, severe illness, hospitalization and mortality for young people who are immunosuppressed, including lung transplant (LTx) recipients. The aim of this study was to explore the intersection between immunosuppression and COVID-19, through the impacts of the pandemic upon the daily lives of young LTx recipients residing in the Australian state of Victoria.

Methods: An exploratory qualitative research study was undertaken via consumer engagement. A purposive sample of 11 LTx recipients, residing in Victoria, was recruited during the first year of the COVID-19 pandemic. Semi-structured interviews were conducted to gain insights into their daily life and healthcare experiences, including the impacts of the COVID-19 pandemic. Data were interpreted using thematic analysis.

Results: Four major themes were identified: (1) occupational deprivation due to the intersection of COVID-19 and lung transplant; (2) resilience and acceptance of restrictions; (3) infection control and vigilance about risk; and (4) care experiences of telehealth.

Conclusions: Occupational deprivation emerged as a common theme, specifically in the context of loss of access to meaningful everyday activities of developmental significance. However, participants also commonly reflected upon their ability to flexibly adjust to changing socially regulated community and healthcare environments. A high degree of acceptance and compliance with public health orders was self-reported, may be indicative of this cohort's long-term experience of chronic illness and their understanding of the importance of minimizing infection risks. Youth-informed healthcare strategies were identified as keystone to engaging them in institutional change and program adaptation during a pandemic.

KEYWORDS

adolescent, COVID-19, immunosuppression, lung transplantation, qualitative research, young people

Abbreviations: LTx, lung transplant.

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1 | INTRODUCTION

The SARS-CoV-2 (COVID-19) pandemic has significantly impacted the lives of adolescents and young people¹. Young people have experienced significant social and economic impacts, with high rates of psychological distress (alongside an increased demand for mental health and telephone counselling services), social isolation, unemployment and educational disruption being reported.¹⁻⁵ Whilst the incidence of severe illness and mortality amongst young people remains low, lung transplant (LTx) recipients experience an increased risk of infection, severe illness, hospitalization and death as a result of COVID-19 transmission.⁶⁻¹¹ Despite a recent body of evidence documenting the impact of COVID-19 on allograft function, the broader impact of the pandemic on the daily lives of LTx recipients has remained underexplored.¹²

On March 11 2020, the World Health Organization declared COVID-19 a global pandemic.¹³ This study was undertaken in the first year of the pandemic at a time when over 79 million cases and 1.7 million deaths were reported globally.¹⁴ In Australia, the first local case was reported in January 2020, and by December 2020, approximately 28 600 cases had been reported nationwide with young people aged 15-24 years accounting for 15% of the infected population.¹⁵ In March 2020, federal and state governments instigated pandemic response orders with wide-ranging restrictions upon community mobility in an attempt to contain increasing infection rates. Border closures, mandatory face coverings, stay-at-home directions and the closure of non-essential services were introduced.^{16,17} The pandemic also led to operational changes in healthcare delivery through the widespread adaptation of outpatient consultations and clinical care to a remote telehealth service model for patients, including LTx recipients.¹⁸ In this study, we examined the impact of the COVID-19 pandemic on the daily lives of young people who had previously received a LTx in Victoria, Australia.

2 | METHODS

2.1 | Study design

The findings outlined herein are part of a larger exploratory qualitative study that was conducted to address the following objectives:

1. To explore the experiences and insights of young people who have undergone lung transplantation and are managed in an adult centre.
2. To gain insights into the factors that young people perceive to influence their quality of life, health and well-being and use this information to develop strategies and processes by which to improve their clinical care.

In this article, we address the research question: How did COVID-19 impact the life and well-being of young lung transplant

recipients? The study was undertaken at a large-volume medical centre that provides LTx to children and adults. A project advisory group comprising of six clinicians, one carer and two LTx recipients provided advice on the design of the research including the interview guide and recruitment.

This study was approved by the Alfred Hospital Ethics Committee (Project Number: 764/19).

2.2 | Participants

A purposive sample of 16 young transplant recipients was recruited. Recipients aged 15-29 who underwent LTx aged ≤ 25 years were eligible. Exclusion criteria included: (1) Primary language other than English; (2) intellectual or learning disability preventing the provision of informed consent; or (3) being less than 6 months post-transplant and medically vulnerable. This article reports the insights of participants who resided in both metropolitan Melbourne ($n = 10$) where pandemic restrictions were greatest, and regional Victoria ($n = 1$). Participants from the broader study who lived interstate, where restrictions were absent, were excluded from the analysis ($n = 5$).

2.3 | Data collection

Semi-structured Interviews were conducted remotely via Zoom or telephone by one of four researchers (K.H., H.M., D.A. and S.W.) between June to December 2020 during Victoria's protracted second lockdown period. Interviews lasted between 37.77 and 91.67 min (Mean = 57.24 min) and were audio-recorded and transcribed for analysis.

2.4 | Qualitative analysis

Thematic analysis was conducted via a process of inductive and deductive coding to identify and categorize themes.¹⁹ One researcher (K.H.) analysed all 11 interview transcripts, with a random 20% independently double-coded by a second researcher (D.A.) and two researchers (M.P. and S.W.) read all transcripts and reviewed the analysed themes. Any disagreements were resolved through discussion. All qualitative analyses were undertaken in NVivo.²⁰

3 | RESULTS

3.1 | Demographics

All 11 participants provided reflections of how pandemic restrictions impacted their daily lives. A summary of the sample's demographic characteristics has been provided in [Table 1](#).

TABLE 1 Summary of participant's demographic characteristics

Demographic characteristic (n = 11)	Descriptive statistics
Age (years): Mean (SD), Range	
Age at interview	23.7 (3.9), 16.1 – 28.6
Age at transplant	17.6 (4.7), 9.5 – 25.3
Years since transplant	6.0 (4.0), 1.0 – 14.3
Gender: N (%)	
Male	3 (27.3)
Female	8 (72.7)
Indication for transplant: N (%)	
Cystic fibrosis	4 (36.4)
Pulmonary arterial hypertension	4 (36.4)
Other health conditions ^a	3 (27.4)

^aOther health conditions included congenital heart disease, interstitial lung disease and obliterative bronchiolitis.

3.2 | Description of major themes

Four overarching themes emerged: (1) Occupational deprivation due to the intersection of COVID-19 and lung transplant; (2) resilience and acceptance of restrictions; (3) infection control and vigilance; and (4) care experiences of telehealth. An overview of the themes and subthemes, alongside complete quotations has been provided in the [Supplemental File](#).

3.2.1 | Theme 1. Occupational deprivation due to the intersection of COVID-19 and lung transplant

Occupations are activities and tasks that provide structure, meaning, purpose and pleasure to our lives.²¹ Occupational deprivation is the preclusion from participating in occupations of necessity, obligation and choice emanating from external factors outside an individual's control and can significantly affect an individual's health, well-being and life satisfaction.^{22,23} Participants who resided in metropolitan Melbourne reported significant and sustained disruption to employment, education, self-care and leisure pursuits; *"Unfortunately, because of COVID, I had to give up nursing"* (LTx7, F). Those classified as non-essential workers were stepped down from their roles or transitioned to working from home; *"I got the job and it was the day I was meant to start and we all went into lockdown. So, I've been stood down."* (LTx3, F). For seven participants, the impact of COVID-19 highlighted their perception of social difference because of transplant, and the effect of this upon daily occupations:

I haven't been on placement this year because coronavirus is an infectious disease and sometimes I feel held back a bit because I can't be the average student or the average person that can go out there
(LTx9, F).

The loss of ability to participate in meaningful activities was described by respondents as personally challenging; *"I was starting to come out of my shell just before lockdown and now I'm coming back into it again"* (LTx1, F). For example, participants who were physically active expressed their disappointment in the closure of relevant exercise facilities (e.g. gyms, swimming pools); *"I'm usually an active person...I just miss going to the gym every day"* (LTx1, F). Some participants managed the negative impacts of restrictions via activity adaptation:

I like to pretend that we're not in COVID. So, on a Friday night, I'll get all dressed up, I'll do my makeup, I'll do my hair and then again, I'll just sit on my bed and watch Netflix
(LTx3, F).

For others, occupational deprivation became a catalyst to explore alternative activities that provided meaning to their day and occupational flexibility became an unintended consequence of deprivation:

I've had a lot of time just because of COVID, I've been home a lot as well. I've got back into art and it's really nice and I do it every day now, painting and stuff, and I'm getting better at it
(LTx5, F).

3.2.2 | Theme 2. Resilience and acceptance of restrictions

Participants discussed efficacious coping skills, as they were used to adapting to health-related changes. Historical health experiences leading to transplant and an immunocompromised status post-transplant were described as informal *"preparation"* for pandemic restrictions. This was particularly relevant to long periods of social isolation, boredom and loneliness, related to occupational deprivation. Five participants perceived this social difference as a lifelong characteristic of living with chronic illness, which was now more intense with the overlay of COVID-19:

I think one thing [people living with Cystic Fibrosis] definitely have and probably also transplants, is that you are so isolated. You are so isolated, it's outrageous. Even more so now
(LTx6, M).

Two participants reflected that restrictions had minimal impact on their daily lives as they typically limited their movement before the pandemic to reduce infection risks; *"I had a lot of complications [post-transplant], so I was pretty much home all the time anyway"* (LTx4, F).

Despite physical social isolation, six participants described restrictions as having presented them with the opportunity to feel as if they belonged to a broader community experience, rather than feeling like an individual outsider:

In this COVID time, everyone is going through a shit one; everyone is going through a tough time at the moment. If you are normal, if you are sane in mind, you should be going through a tough time and it should be pretty challenging

(LTx6, M).

Technology was identified by nine participants as: Fostering social connectedness; a means of remote employment; and a mode for remote education; *"I think everyone has technology. It's easy to be like, 'I'll just FaceTime you'"* (LTx,3, F). Although the flexibility of remote learning was discussed, one participant expressed their difficulty in adjusting to this mode of education; *"I'd rather be at school...I find it's just easier to concentrate on the task at hand"* (LTx11, M).

One participant reported using this time to *"give back to the community"* by sewing masks and selling them to others, and found comfort in contributing to a safer community during the pandemic:

I'm actually really good at sewing...I started the masks and once I posted one, everyone was like, 'Oh, do you mind making me one?' So, I started doing it for everyone, which is good because then at least everyone's a bit safer

(LTx3, F).

3.2.3 | Theme 3. Infection control and vigilance about risk

All participants recognized the intersection between their immunosuppression and COVID-19 with reference to the increased risk of infection and significant illness. Participants responded to this heightened risk with hypervigilant infection control behaviours; *"With COVID and stuff, I am a lot more alert"* (LTx11, M). Strategies to limit possible COVID-19 infection included: Attending pathology appointments as the first patient of the day; minimizing outpatient face-to-face appointments; wearing a mask even when not mandated; depending upon family or significant others to purchase daily items; and restricting interactions with persons outside their own home.

There was general acceptance of public health orders as a means of protecting participants, as vulnerable members of the community. Concern for an unknown future was accompanied by beliefs that the pandemic would be a short-term transient phenomenon and as such the threat would abate; *"It's okay, you do what you have to for the moment"* (LTx4, F). For some, pandemic restrictions 'normalised' post-transplant life. They commented that public health recommendations were measures they regularly followed despite the pandemic; *"everyone is whinging about the hand sanitiser and keeping their distance from people...that's been normal for us for years"* (LTx9, F). In response to greater levels of transmission in metropolitan Melbourne, the participant who resided in regional Victoria expressed their hesitancy towards travelling to Melbourne; *"I live in regional Victoria, so we don't*

actually have any cases here...coming to Melbourne is very scary for me" (LTx8, F). One participant reflected upon the need to; *"use your common sense really and just be careful"* (LTx5, F).

Finally, one participant reported an expectation for a lowered risk of infection in the community and hypothesized that a subsequent decrease in respiratory infections would be observed due to the increased awareness of infection control and the uptake of prevention measures amongst the general population as a result of the pandemic".

I reckon cold and flus will be potentially a little bit less...by the fact that people will probably be a bit more aware of their hand hygiene or whatever

(LTx6, M).

3.2.4 | Theme 4. Care experiences of telehealth

Telehealth emerged as a preferential infection control modality for healthcare; however, participants described mixed feelings and experiences with telehealth. Three participants described positive aspects, including: Ease of access to care; time efficiencies as taking time off school/work to travel to a health facility as not required; reduced waiting times in digital waiting rooms compared to in-person settings; and elimination of potential infection risks. One participant expressed that while telehealth was a convenient and flexible method of healthcare delivery, there were limitations in its delivery associated with the time-sensitive pressures for healthcare systems to adapt:

I don't think telehealth is done as well as it could be, but that's a sign of the fact that it had to be set up in the middle of a pandemic

(LTx7, F).

Four participants reflected upon negative features of telehealth, particularly a lack of human face-to-face interactions; *"I do prefer to see the person I'm talking to. I definitely think it's better to have a face-to-face or at least a video telehealth appointment"* (LTx4, F). For these participants, telehealth was described as a poor substitute to previous care experiences, with which they had felt comfortable and safe.

4 | DISCUSSION

To our knowledge, this is the first study reporting the impact of the COVID-19 pandemic on the daily lives and healthcare experiences of young people with a LTx. Interviews occurred during a 4-month lockdown in Victoria, with no available vaccine, culminating in significant community dislocation from sources of work, education, leisure and social interaction.

Occupational deprivation has been described as; *"a state of preclusion from engagement in occupations of necessity and/or meaning*

dues to factors outside the immediate control of the individual" (pp. 201).²² Young LTx recipients reported impacts upon their daily lives similarly experienced by immunocompetent youth.¹⁻⁴ Deprived of access to the world outside their home environment, many participants described the loss of opportunities for life skills mastery typically associated with the transition from adolescence to young adulthood. Some participants described their unique health status as accentuated by the pandemic, while others reflected a sense of belonging to a broader, social experience. They referred to restrictions as having normalized their lived experience of an immunosuppressed lifestyle, reflecting that the disabling of life choices and activities was a broader social phenomenon resulting from pandemic restrictions, rather than transplant itself.

Recent research suggests that adult LTx recipients are responsive, resilient and adhere to public health measures aimed at reducing COVID-19 transmission.¹² Similarly, we found a high level of acceptance and adherence amongst our cohort who reflected an understanding that they, as a health-specific group, were vulnerable to COVID-19 infection due to immunosuppression. Additionally, our results suggest that adherence to restrictions may be attributed to the cohort's long-term experience of living with chronic illness and understanding the importance of minimizing infection risk. While cohort studies have indicated that the incidence of COVID-19 infection among transplant recipients is low,⁶⁻¹⁰ our results suggest that recipients' acceptance of the social climate of the pandemic, in addition to adherence to public health directions, may play a protective and preventive role in reducing infection; a phenomenon also reported in other groups with chronic disease.²⁴

Insights into the effect of the pandemic on healthcare experiences were also provided, with particular reference to the adoption of telehealth as a substitute for face-to-face healthcare.¹⁸ In Australia, telehealth was supported by federal government funding changes to the nationalized healthcare model.²⁵ Consumers have previously described both the positive (e.g. ease and convenience) and negative aspects (e.g. challenges in communication, including lack of eye contact and difficulties in responding to non-verbal body language) of these modalities.²⁶ This was similarly reflected in our cohort who valued the convenience, but felt the loss of continuity and familiarity associated with face-to-face consultations.

4.1 | Strengths and limitations

The participatory nature of this study was a significant strength that enabled us to gain an initial understanding of the impacts of the COVID-19 pandemic on this cohort. Another strength was the ability to leverage technology to conduct this study remotely during a public health crisis when movement in the community was restricted, allowing us to collect data in real-time, rather than retrospectively. The results, however, should be interpreted within the context of several limitations. Although the impact of the COVID-19 was an area of inquiry during the interviews, this was not the central focus of the broader project and as such these findings are preliminary.

Furthermore, the small sample size limited the generalizability of the conclusions drawn, while acknowledging that the impacts on this cohort may be broader than we have identified. Recent research has highlighted the significant impact of the pandemic's social climate on the psychological well-being of adult LTx recipients^{27,28}; however, additional research specifically exploring the social and mental health impacts on young LTx recipients is needed to clarify these impacts and inform the response of the healthcare system to best support their needs in such times of crisis. Despite these limitations, the findings of this study are unique in that they have provided insight into these impacts in a country that has experienced significant restriction on community movement.

5 | CLINICAL IMPLICATIONS AND CONCLUSION

For adolescent LTx recipients, post-transplant outcomes continue to be poor compared to those of adults, with a lower expectancy of survival.²⁹ Youth-informed strategies to redesign healthcare during public health crises may contribute to improving outcomes, including: (1) Ensuring an active voice of youth in the modality and delivery of their own healthcare; (2) individuating care programs; (3) providing video-based telehealth in the absence of face-to-face care; (4) consider face-to-face healthcare for socially vulnerable youth, as not all young people have private and safe spaces within their home for telehealth³⁰; (5) leverage technology as an accessible and effective modality for health literacy, care and psychosocial support to engage youth in their own care; and (6) ensure the constancy of clinicians to foster effective relationships of trust.

This study has focussed upon youth living with an immunosuppressed lifestyle in a time of a virulent and everchanging virus. Occupational deprivation may have stalled significant life transitions typically associated with youth; however, this study has identified that participants' experiences were not wholly negative. Outcomes of this study, from the perspective of young LTx recipients during the first year of the pandemic, may assist to mitigate negative long-term sequelae of COVID-19 upon the developmental continuum of transplanted youth.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

AUTHOR CONTRIBUTIONS

Study design and conception: MP, DA and SW; Recruitment and data collection: KH, HM, SW and RM; Data analysis: KH, DA, SW and MP;

Drafting/writing of the manuscript: KH, SW, MP and DA; Revising drafts: All authors.

DATA AVAILABILITY STATEMENT

The qualitative data that support the findings of this study are not openly accessible due to privacy or ethical restrictions and to preserve the anonymity of participants. Supporting deidentified quotations have been provided in the body of this article and the supplemental material.

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ENDNOTE

¹ Aged 12–24 years and henceforth referred to as “young people”.

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