OPTN Lung Transplantation Committee
Updating Mortality Models Subcommittee
Meeting Summary
April 22, 2021
Conference Call

Erika Lease, MD, Chair
Marie Budev, DO, Vice Chair

Introduction

The Lung Transplantation Committee's Updating Mortality Models Subcommittee met via Citrix GoTo teleconference on 04/22/2021 to discuss the following agenda items:

1. Review of current Lung Allocation Score (LAS) values

The following is a summary of the Subcommittee's discussions.

1. Review of current Lung Allocation Score (LAS) values

The Subcommittee reviewed how the current data fields are reflected on the LAS form in Waitlist[SM] and noted areas that are in need of updates and specifically what types of updates are needed for each field. The Chair clarified that there will be a future discussion for the addition of new fields, but the purposes of this meeting is to revise the current fields while noting fields that may need to be added.

Summary of discussion:

Lung Diagnosis Codes

The Subcommittee covered the addition of possible diagnoses including an option for a combined Pulmonary Fibrosis and Chronic Obstructive Pulmonary Disease (COPD) diagnosis since that is currently captured as part of Idiopathic Pulmonary Fibrosis (IPF) which does not accurately capture the risk of mortality for those candidates. SRTR staff noted that these candidates often do not appear urgent, but there is a considerable risk for mortality on the waitlist that may be different than IPF. The Chair stated that the current data suggests that the waitlist mortality of these candidates is relatively high.

The Subcommittee requested a report out from the Lung Review Board to get information on how often diagnoses that are not currently included request diagnoses exceptions for future consideration and supported having regular check-ins to be more informed regarding the trends in exception requests.

The Subcommittee mentioned that there may be a need for an additional viral diagnosis option outside of the COVID-19 diagnosis. The Chair stated that the "Pulmonary Fibrosis: Other" is used and the Vice Chair agreed, but mentioned it may need to be made more granular as possible future pandemics occur.

Functional Status

The Subcommittee discussed options to improve consistency across transplant programs when reporting this information since the current process has variation across programs. Members noted that many programs utilize the Karnofsky Performance Status Scale and it may be helpful to divide that into

thirds for guidance (0-40, 50-70, 80-100).[1] A member noted that the Karnofsky Scale may not be appropriate for all patient types, such as smaller pediatric candidates since there is often some assistance since they do not function independently. Members supported leaving the drop-down as is, but providing more guidance on how to map Karnofsky scores to the existing scale within the help documentation in order to help with consistency in reporting.

Diabetes

The Subcommittee discussed ways to simplify this field while still capturing enough granularity to be meaningful. The Vice Chair asked for clarification on the "dependency unknown" category and a member stated that steroid use causes an unknown dependency. The Vice Chair mentioned that the use of "dependency" is complicated since there are many options regarding insulin use. Members asked how diabetes is used in the LAS calculation and it was clarified that the coefficient for diabetes would be removed in the future. SRTR staff noted that insulin use has a higher risk of mortality so that distinction needs to be made. The Subcommittee supported narrowing the field to "diabetic" (yes/no) and if yes, "treated with insulin" (yes/no).

Assisted Ventilation

Members discussed what possible updates may need to be incorporated for data collection regarding Extracorporeal Membrane Oxygenation (ECMO) and modality (i.e. ambulatory or non-ambulatory). It was noted that the reporting regarding ECMO at time of removal was available that may help inform Subcommittee decisions.[2]

The Subcommittee discussed whether both Bilevel Positive Airway Pressure (BiPAP) and Continuous Positive Airway Pressure (CPAP) devices were needed. A member stated that CPAP is typically used primarily at night for Obstructive Sleep Apnea and suggested having BiPAP continuous versus nocturnal use and not having as much detail for CPAP. It was clarified that the only option in the drop-down that has a coefficient for LAS is "continuous, mechanical, hospitalized". The Chair stated that the concern is individuals who are using near continuous BiPAP are not being captured well enough to distinguish them from the individuals using nocturnal BiPAP.

SRTR Staff stated that best describing these categories is important because the types of assisted ventilation have a major effect on a candidate's mortality risk and that needs to be accurately captured. The Subcommittee noted that they would need to try to categorize the types of devices in a way that makes sense clinically for transplant coordinators while not identifying specific devices.

Supplemental O_2

The Subcommittee discussed opportunities for consistency in capturing supplemental O_2 at rest, at night, and with exertion and the need to take into account that each type of device is different. The Chair stated that there needs to be a way to distinguish between patients who are on 2 liters of O_2 at rest and remain on 2 liters after exertion versus 15 liters after exertion. A member stated that it may be difficult to define exertion for consistency, but recognized the need to distinguish after exertion O_2 usage.

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[1] Karnofsky Performance Status Scale Definitions Rating (%) Criteria. Accessed May 19, 2021: http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf

[2] Monitoring Collection of Extracorporeal Membrane Oxygenation (ECMO) Data Upon Waitlist Removal for Lung Candidates. OPTN Thoracic Committee, Descriptive Data Request, Submitted October 25, 2018.

The Chair stated that the delivery devices used are sometimes different for at rest versus exertion, so the device type should be added for exertion and additionally capture both liters and Fraction of Inspired Oxygen (FiO_2) with high-flow devices. Members noted that the upper limit for O_2 needs to be increased since patients are commonly on more than 26 liters. The Subcommittee felt that a new upper limit of 60 liters seemed reasonable.

The Subcommittee supported separating device types into categories such as nasal cannula/high flow nasal cannula, reservoir cannula, and face mask. The Subcommittee also supported removing the field for "how the value was obtained" since the options will no longer be needed due to having the options for liters per minute and FiO_2.

Next steps:

UNOS Staff will work on a mock-up form including suggestions from this meeting and will reach out to the Lung Review Board about joining a future meeting.

Upcoming Meeting

- May 27, 2021

Attendance

- **Subcommittee Members**
  - Erika Lease, Chair
  - Marie Budev, Vice Chair
  - Whitney Brown
  - Dennis Lyu
  - John Reynolds
  - Marc Schecter
  - Staci Carter
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Katie Audette
  - Melissa Skeans
  - Maryam Valapour
- **UNOS Staff**
  - Julia Chipko
  - Rebecca Goff
  - Elizabeth Miller
  - Janis Rosenberg
  - Leah Slife
  - Sara Rose Wells
  - Krissy Laurie
  - Tatenda Mupfudze