OPTN Lung Transplantation Committee
Updating Mortality Models Subcommittee
Meeting Summary
May 27, 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 05/27/2021 to discuss the following agenda items:

1. Review of Lung Review Board Exception Types
2. Review of Current LAS Values and Mock-Up with Discussed Revisions
3. Discussion of Future Data Field Additions

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

1. Review of Lung Review Board Exception Types

The Subcommittee reviewed the number of lung exception requests by diagnosis from 2019-2020. The most commonly used diagnosis for exception requests was pulmonary hypertension/pulmonary arterial hypertension. The Vice Chair noted that the higher usage of cystic fibrosis (CF) as an exception was likely related to a publication released by the CF Foundation that changed how CF patients were viewed by lung transplant programs.[1] Members expected the numbers for pulmonary hypertension and mentioned that the cases with only one or two within the two year span are understandably rare and unique occurrences. The Chair and Vice Chair requested more detailed information for review on the requests for chronic obstructive pulmonary disease (COPD) and idiopathic pulmonary fibrosis (IPF) to better understand the specifics of the patients' diagnosis.

2. Review of Current LAS Values and Mock-Up with Discussed Revisions

The Subcommittee reviewed the mock-up with the suggested revisions from the April 22, 2021 meeting and approved of the changes.[2] The Subcommittee was asked for feedback on whether or not there should be additional evaluation dates for supplemental O_2 "With Exercise" and "At Night" even though only the "At Rest" data is used for the LAS calculation. The Chair clarified that those three values are typically all updated at once, so having the one evaluation date is appropriate.

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[1] Kathleen J. Ramos, Patrick J. Smith, Edward F. McKone, Joseph M. Pilewski, Amy Lucy, Sarah E. Hempstead, Erin Tallarico, Albert Faro, Daniel B. Rosenbluth, Alice L. Gray, Jordan M. Dunitz, and CF Lung Transplant Referral Guidelines Committee, "Lung transplant referral for individuals with cystic fibrosis: Cystic Fibrosis Foundation consensus guidelines, " *Journal of Cystic Fibrosis* 18, no. 3 (May 2019): 321-333, https://pubmed.ncbi.nlm.nih.gov/30926322/

[2] "OPTN Lung Transplantation Committee, Updating Mortality Models Subcommittee Meeting Summary (April 22, 2021),"OPTN, accessed June 17, https://optn.transplant.hrsa.gov/media/4620/20210422_lung-umm-subcommittee-meeting-summary.pdf

The Subcommittee continued their review of 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.

Summary of discussion:

Pulmonary Function Test Date

The Chair referenced removing "Post Bronchodilator Actual FEV1" and "Post Bronchodilator Percent Predicted FEV1", since it was previously discussed that those fields are not being used and there were questions on the value of the data. The Chair also referenced the inclusion of the percent predicted versus having that calculated automatically and possible concerns with that. The Vice Chair mentioned that the previous discussion referenced concern with how patient biology and demographics are captured with the methodology used by laboratories for those values. The Subcommittee supported this based on previous discussion.

Six Minute Walk Distance (6MW)

The Chair suggested moving the "Six Minute Walk Distance" field below "Requires Supplemental O_2" since those fields are typically collected at the same time with the same tests and entered at the same time by transplant coordinators and the Subcommittee agreed with this refinement.

The Subcommittee was asked for feedback on whether or not additional information should be included for the 6MW field such as if the patient required supplemental O_2 during the test and the Chair clarified that information would be included in the "Requires Supplemental O_2, With Exercise" field.

Most Recent Heart Catheterization Date

The Subcommittee confirmed that all values related to heart catheterization would be collected on the same date. The Chair asked for clarification on why "Central Venous Pressure (CVP)" was not indented under the heart catheterization data and the Vice Chair added that there are rare occurrences where the value is pulled off of the Swan-Ganz catheterization.

The Chair noted that they would not change the data captured with the heart catheterization data and asked if all of those fields were required. It was clarified that all of the fields are optional and do not expire, with the only exception being "Pulmonary Capillary Wedge Mean" becoming a mandatory field with a diagnosis of sarcoidosis.

Current Blood Gas Information

The Vice Chair suggested clarification for "O_2 Amount (L/min or %)" since high flow machines should enter both fields and the Subcommittee supported editing the field to and/or for the instances that there is data for both. The Chair noted that the 26 liter max should also be adjusted to the new recommended max of 60 liters. A Member asked if we should capture mechanical ventilation settings or possibly positive end-expiratory pressure (PEEP), and the Chair noted we are not capturing this information and could discuss that as an addition, while still staying away from programs doing calculations, but instead adding the raw data. A Member asked how extracorporeal membrane oxygenation (ECMO) and the supplemental O_2 level would be entered and the Chair clarified that the candidate would still receive the points once ECMO was selected as assisted ventilation, but any specification on blood gas/O_2 usage would be for data collection.

3. Discussion of Future Data Field Additions

Initial feedback on additional fields for discussion included factors relating to CF patients, capturing data on ventilation settings if that could change how we calculate medical urgency, microhistory, patients with prior lung volume reduction surgery, and delta change for fields such as the 6MW.

The Chair noted that there was information that suggested the delta change in FEV_1 for COPD predicted mortality in patients and offered to review that information to see if there is an option to include that as data collection. A member also suggested collecting information on hemoptysis since that is also a factor for increased mortality and the Vice Chair noted that it should be included for every disease. The Vice Chair and a member mentioned that poor prognostic indicators should be researched for each diagnosis and be considered for data collection. The Vice Chair suggested researching ways to capture combined COPD/IPF patients since they are not captured through diagnosis.

The Chair mentioned wanting to look at other diseases where specific changes over time are poor prognostic indicators. A member noted there is information regarding delta change in the 6MW is an indicator of disease progression. The Vice Chair stated that there is typically 6MW testing data that is performed prior to listing that can be collected here.

A member noted that microhistory may be hard to categorize but would be helpful data, as well as information about prior chest surgery. The Chair mentioned that pan-resistance is captured, but asked if that information is being utilized currently. The Chair also agreed that prior chest surgery should be captured since the member explained those are often higher risk patients.

The Subcommittee will reference the literature and provide additional information for consideration at the next meeting.

Upcoming Meeting

- June 24, 2021

Attendance

- **Subcommittee Members**
    - Erika Lease, Chair
    - Marie Budev, Vice Chair
    - Whitney Brown
    - Dennis Lyu
    - John Reynolds
- **HRSA Representatives**
    - Jim Bowman
    - Raelene Skerda
    - Adriana Martinez
- **SRTR Staff**
    - Katie Audette
    - Melissa Skeans
- **UNOS Staff**
    - Janis Rosenberg
    - Leah Slife
    - Sara Rose Wells
    - Krissy Laurie
    - Tatenda Mupfudze
    - James Alcorn
    - Susan Tlusty