Lung transplantation waitlist disparities for children with cystic fibrosis

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Background: With no previous research evaluating whether disparities influence outcomes in children with cystic fibrosis (CwCF) on the waitlist for lung transplantation (LTX) or who undergo LTx in the United States, we explored this important question using a national registry. We examined whether survival differences exist between white non-Hispanic (WNH) and non-white (NW) (black, Hispanic, Asian, other) CwCF on the waitlist for LTx or who underwent LTx.

Methods: The United Network for Organ Sharing Registry was queried for CwCF (aged <18) who had been waitlisted for or underwent LTx between January 1, 2000, and December 31, 2021. Chi-square and nonparametric median tests were used to compare categorical and continuous variables, respectively. Data are presented as medians with interquartile ranges (IQRs). Statistical significance was defined as p < 0.05.

Results: Eight hundred twenty-eight CwCF were on the waitlist for LTx (660 WNH, 198 NW). WNH CwCF were older (age 15 [12–16] vs 14 [10.25–15], p < 0.001), taller (150 cm [138–157.5 cm] vs 146.6 cm [128.8–154.9 cm], p = 0.02), and on the waitlist longer (180 [41–540.25] days vs 109 [31–349] days, p = 0.001). There were no differences in sex, body mass index (BMI), weight, lung allocation score, or mean pulmonary artery pressure between the two cohorts. NW CwCF (n = 47, 27.9%) were significantly more likely to die on the waitlist or be removed from it because their condition was deteriorating than WNH CwCF (n = 123, 18.6%) (p = 0.007). There was no difference between the two cohorts for removal for undergoing LTx or improved condition (WNH: n = 455, 68.9%; NW: n = 104, 61.9%; p = 0.08) or other/unknown (WNH: n = 82, 12.4%; NW: n = 17, 10.1%; p = 0.4). Figure 1 shows Kaplan-Meier survival curves for WNH and NW CwCF on the waitlist for LTx (Figure 1a) and after LTx (Figure 1b). Cox proportional model multivariate analysis for the key clinical variables (age, height, weight, BMI, lung allocation score, mean pulmonary artery pressure) for NW and WNH CwCF did not identify significant confounders contributing to waitlist survival. There was no difference in post-LTx survival between NW (mean survival: 3099 days, 95% CI, 2304–3876 days) and WNH (mean survival: 3055 days, 95% CI, 2727–3393 days) children (p = 0.8) (Figure 1b).

During this same period, there were no disparities found in waitlist outcomes between WNH and NW CwCF on the waitlist for LTx or who underwent LTx.

Conclusions: A significant LTx waitlist disparity for NW CwCF was identified. Despite the fact that advances in CF transmembrane conductance regulator (CFTR) modulator therapy have greatly affected the pediatric CF population and reduced the need for Ltx in WNH CwCF, we anticipate the need for LTx to continue in NW CwCF until specific discoveries can address the more common CFTR mutations in the NW CF population. There is a pressing need to address the waitlist disparity in NW CwCF, given the impact of this issue.

Acknowledgements: This work was supported by National Institutes of Health R01HL142210 (AZ), R01HL151588 (AZ-MPI), and R01HL147957-01.

Lung Transplant READY: Pilot randomized clinical trial of a self-directed patient-facing lung transplant education website

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Background: People with cystic fibrosis (CF) face uncertainty when considering lung transplantation (LTX) in the era of highly effective CF therapeutics. Our team created Take on Transplant (ToT), a web-based educational resource that provides personalized, up-to-date, guideline-based LTx content alongside personal narratives from individuals with CF and caregivers. We compared ToT with more general transplant education resources from the United Network for Organ Sharing (UNOS) website (unos.org) on preparedness for LTx discussions in a pilot randomized clinical trial (RCT). Recruitment of participants was focused on those with disadvantaged access to LTx.

Methods: This was a pilot randomized, single-blind, rollover study to assess feasibility and evaluate the effect of ToT on preparedness for LTx discussions, measured using the Preparation for Decision Making Scale (PrepDM) [1]. Information on demographic characteristics and health literacy were obtained at baseline. Participants were randomized to access one of two websites (ToT or UNOS) for 2 weeks. Serial surveys were performed during study visits via Zoom at baseline, 2 weeks, and 4 weeks to compare ToT efficacy for preparedness and impact on psychological endpoints of the two groups. After the 2-week visit, all study participants gained access to both websites for an additional 2 weeks. We continuously captured individual-level website usage data for all participants throughout the RCT. Participants (n = 50) were adults with CF, a percentage...