

# Texas Children's Hospital cuts waitlist times for pediatric heart transplant patients

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Long waitlist times often lead to a higher risk of death for children awaiting heart transplantation. However, the team at Texas Children's Hospital, Houston, cut wait times by revising their waitlist protocols for donor heart size and patient severity status. Results from this intervention were presented today at the 2015 American College of Surgeons National Surgical Quality Improvement Program (ACS NSQIP) Conference in Chicago.

As of July 2, 2015, more than 320 children nationwide were listed as candidates for [heart transplantation](#), according to the Organ Procurement and Transplantation Network,<sup>1</sup> the national database of people listed for organ transplant, managed by the United Network for Organ Sharing (UNOS).

Heart transplants pose a specific problem in terms of supply and demand. Unlike other organs, such as livers or kidneys, hearts can only be received from deceased donors. Children on the waitlist are prioritized by severity and matched by size to the donor. Previous research has found that up to 17 percent of pediatric heart transplant candidates die on the waitlist and the risk of dying increases the longer one has to wait, thus, the imperative to reduce waitlist time.<sup>2</sup>

Patients at Texas Children's had a median wait time of 128 days in 2013, the team reported. "In an attempt to decrease waitlist time, we felt it imperative to review our current practice for listing patients and identify potential areas for improvement," said Diana Orosco, RN, heart

transplant coordinator at the hospital.

"We asked ourselves, 'Are we being too conservative institutionally with respect to some of the parameters we're using to list our patients?'" explained William J. Dreyer, MD, medical director for the hospital's cardiac transplant program.

The hospital's heart transplant team revised two protocols for this quality improvement (QI) initiative. One focused on expanding the donor size parameters to increase the pool of possible donor hearts available for patients.

The second parameter focused on patient severity status. Heart transplant candidates with the most severe conditions are given an urgency status of 1A. Those with a status of 1B or 2 are considered less urgent and often wait longer for a matching organ.

"Some of our patients don't strictly meet the entry criteria for a 1A or 1B listing status based on the type of illness they have and how they may be managed," Dr. Dreyer explained. "However, a child who doesn't meet the criteria but who is severely ill can undergo an appeal process with the UNOS regional review board."

As part of this QI initiative, the heart transplant team became more proactive about appealing to the UNOS regional review board to assign patients a higher severity status when clinically appropriate.

From January to December 2014, 32 patients—from neonates to teenagers—received a heart transplant at Texas Children's. The team used the Organ Procurement and Transplantation Network database to determine how adjustments on size parameters and appealing for higher listing status impacted wait times.

Results showed patients experienced a significant drop in median waitlist times. Specifically:

- Before the initiative, 19 patients had already been on the waitlist and had been waiting for a median of 181 days. After a change in the size parameter, a status appeal, or both, these patients only waited an additional 56 days to receive a donor heart.
- Twelve patients were added to the waitlist during the initiative with the new parameters for weight or after a severity status appeal. Instead of waiting the typical median of 128 days, these patients waited a median of 31 days to receive their heart transplant.
- One patient did not have an adjustment in either the size protocol or the severity status protocol and was on the waitlist for 444 days.

For this QI initiative, the team is tracking the 32 patients transplanted to determine if the change in waitlist criteria has an impact on both short- and long-term outcomes post-transplant.

These results also have implications for the social challenges families face when a child is waiting for a donor heart. Texas Children's heart transplant team requires [patients](#) actively listed for heart transplant live within one hour of the hospital while they're waiting. "Parents have to quit working or relocate their entire family here. We have some families that are split—one parent is here, the other is back home working. Siblings are split up. It's a major psychosocial strain on family life," said Ms. Orosco. "Having a child who is sick enough to be on the [heart transplant](#) list is stressful enough."

"We were looking at mortality statistics and hoping to impact them," said Dr. Dreyer. "But as a regional center, taking referrals from so many places, there's no question that shortening the waitlist time can also

minimize the social morbidity associated with the [waitlist](#) process."

**More information:** 1. Organ Procurement and Transplantation Network. U.S. Department of Health & Human Services. Available at: [optn.transplant.hrsa.gov/conveyance/testData/rptData.asp](https://optn.transplant.hrsa.gov/conveyance/testData/rptData.asp). Accessed July 9, 2015.

2. Almond CS, Thiagarajan RR, Piercey GE, et al. Waiting List Mortality Among Children Listed for Heart Transplantation in the United States. *Circulation*. 2009; 119: 717-727.

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