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Session MINI ORAL 09 - A Quick Trip Through the Pediatric Heart Function and Transplant Journey

322. A Pediatric Heart Failure Registry is Needed: A Time for ACTION

📅 April 20, 2023, 4:21 PM - 4:25 PM

📍 Rooms 501-504

Topic:

HEART-Pediatrics-Heart Failure

Presenter

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Disclosures

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Abstract or Presentation Description

Purpose While numerous adult heart failure (HF) registries generate data that lead to practice change and improved adult HF outcomes, no such pediatric HF registry currently exists. Despite increased inpatient mortality and resource use for children compared to adults with HF, detailed data regarding pediatric HF profiles and outcomes are lacking. ACTION sought to determine the feasibility of establishing a pediatric HF registry.

Methods ACTION developed a pediatric HF hospitalization registry to prospectively enroll children admitted with acute decompensated HF at 13 pilot sites. Demographic information, laboratory and echo data, hospital outcomes, and hospital re-admission data were collected. A pilot study was launched to assess feasibility using the ACTION infrastructure.

Results There were 112 patients enrolled. The composition of the cohort is described in table 1; 40% had dilated cardiomyopathy. The outcome of the HF hospitalization is depicted in Figure 1; 21 (19%) patients underwent VAD and 29 (26%) patients underwent heart transplant (HT). Overall, 55% of the cohort was discharged without a VAD or HT with a median length of stay of 22 days (Q1-Q3 9-46), and a 30-day re-admission rate of 18%.

Conclusion Establishment of a robust and sustainable multicenter pediatric HF registry is feasible through ACTION that is capable of capturing a wide diversity of pediatric HF syndromes. This effort stands to significantly broaden the reach of ACTION to improve the outcomes of children with HF. HF medication usage has been identified as a priority area for future quality

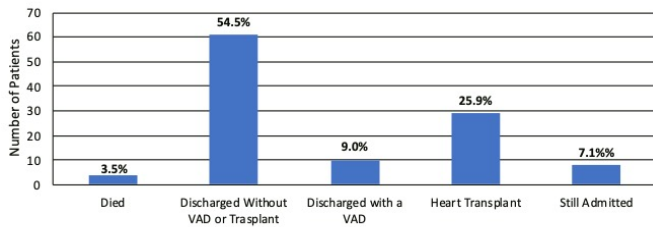
improvement work as an updated version of the registry is currently being expanded to the entire network.

Table 1: Composition of the Heart Failure Registry Cohort

Age in Years (Median/IQR)	11.3 (2.2 – 16.1)
Sex (n,%)	58 (52%) male
Race/Ethnicity	
Non-Hispanic White	51 (46%)
Non-Hispanic Black	21 (19%)
Hispanic	23 (20%)
Missing/Other	17 (15%)
Insurance*	
Medicaid	59 (53%)
Private	49 (43%)
None/Other	7 (6%)
Primary Diagnosis	
Congenital Heart Disease 1-ventricle	26 (23%)
Fontan	21 (19%)
Congenital Heart Disease 2-ventricle	14 (13%)
Dilated Cardiomyopathy	11 (10%)

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Figure 1: Outcome of Heart Failure Hospitalization



VAD: Ventricular Assist Device

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