



# Children With Surgically Corrected Congenital Heart Disease Who Are Long-Stay Intensive Care Patients: An Analysis of Post-Discharge Burden of Care

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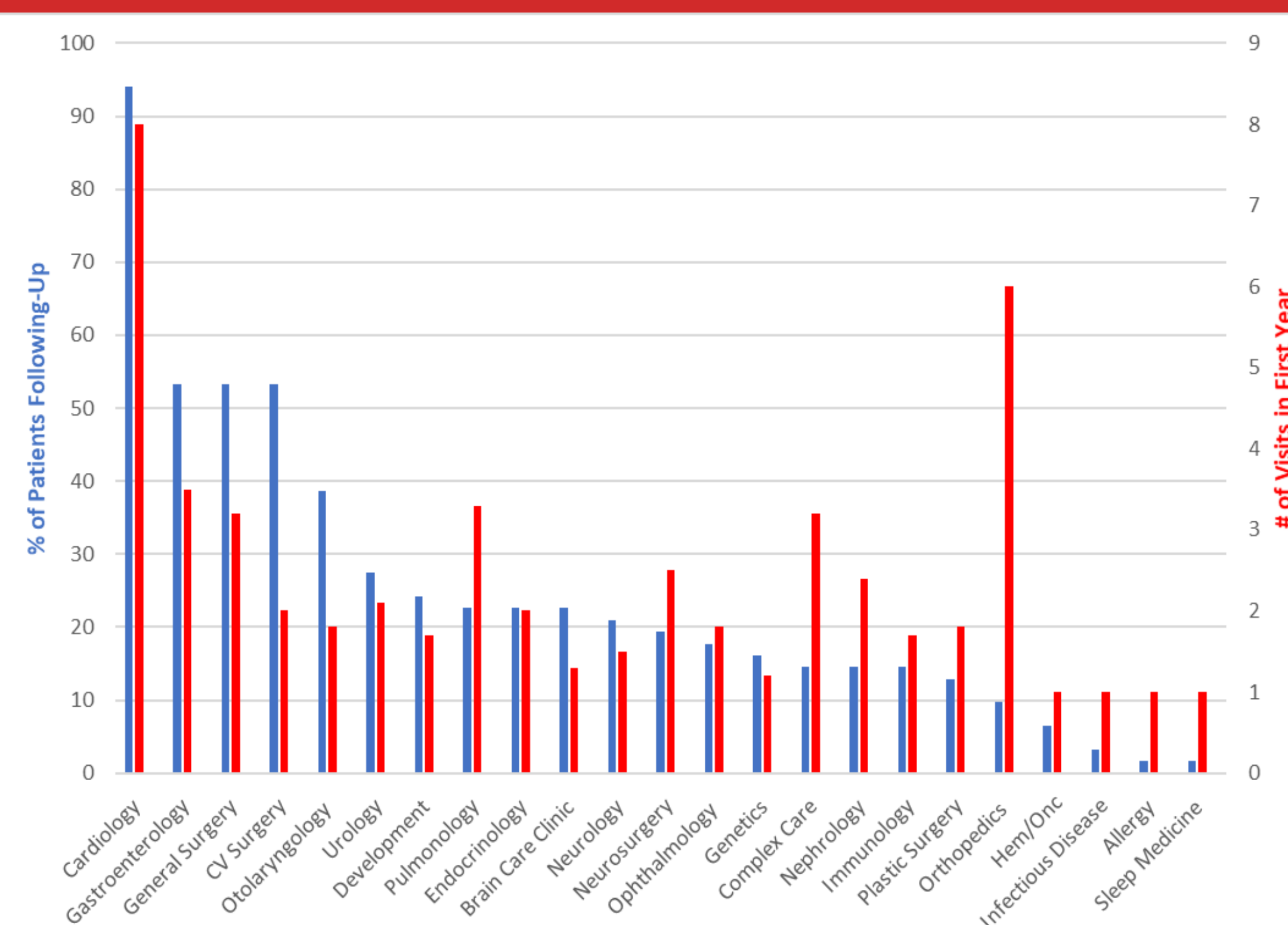
## BACKGROUND

- Many PICU Long Stay (LS, >28 days) patients have congenital heart disease (CHD)
- Many CHD patients have non-cardiac medical problems that affect PICU length of stay (LOS) and post-discharge care
- Health Care Quality of Life has been described in PICU LS patients, but does not describe specific burdens of care
- No studies have described specific post-discharge burdens of care for CHD LS patients

## METHODS

We reviewed the EHR of 69 patients with CHD admitted between 2009 - 2018 to American Family Children's Hospital PICU, underwent cardiac surgery, and had a PICU LOS > 28 days

## Subspecialty Follow-Ups- 1st Year

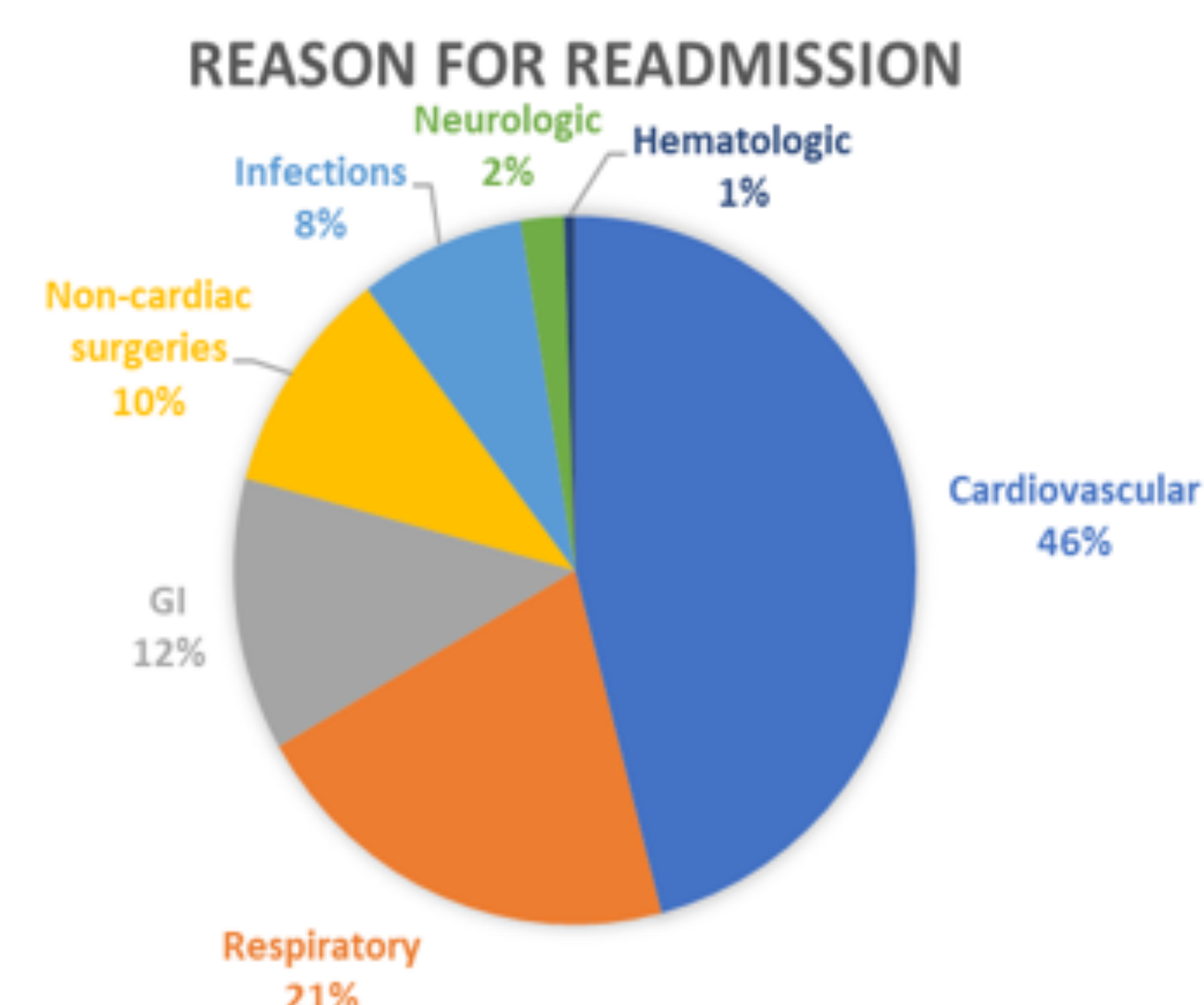


- Followed by an average of 5.2 subspecialists
- Seen an average of 17.8 times

Long-stay PICU patients with congenital heart disease who undergo cardiac surgery have **SIGNIFICANT** burdens of care after discharge

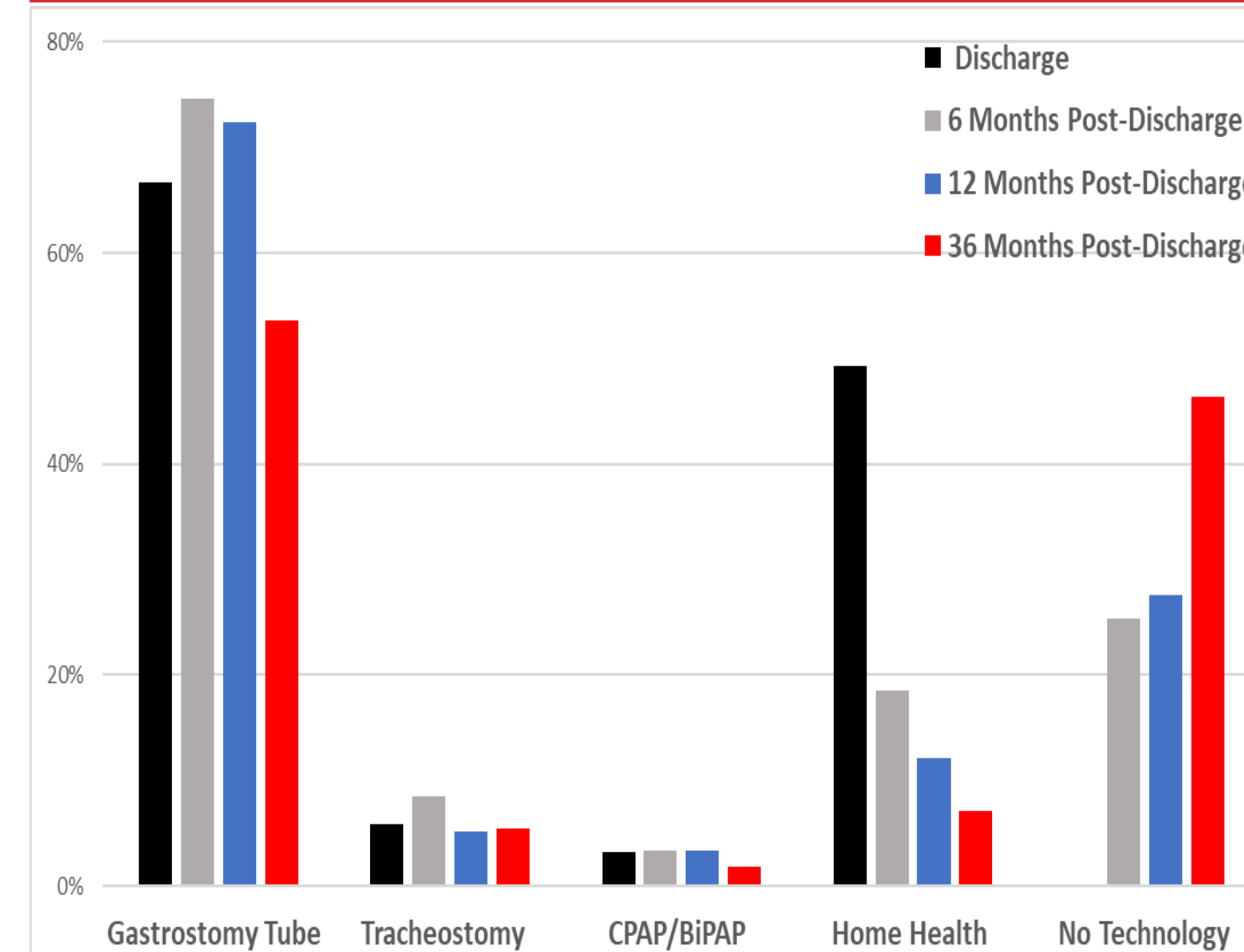
## RESULTS

### Hospital Readmissions- 1st Year



- Initial average PICU LOS was 68.8 days
- 74% of patients readmitted
- Average of 2.8 readmissions per patient
- LOS- 6.3 days per readmission
- Accounts for 17.6 readmission days

### Technology and Services- 3 Years



- >50% of patients require enteral tube at 3 years for nutrition and medications
- <15% of patients need respiratory support

## CONCLUSIONS

### PICU LS patients who have surgery for CHD:

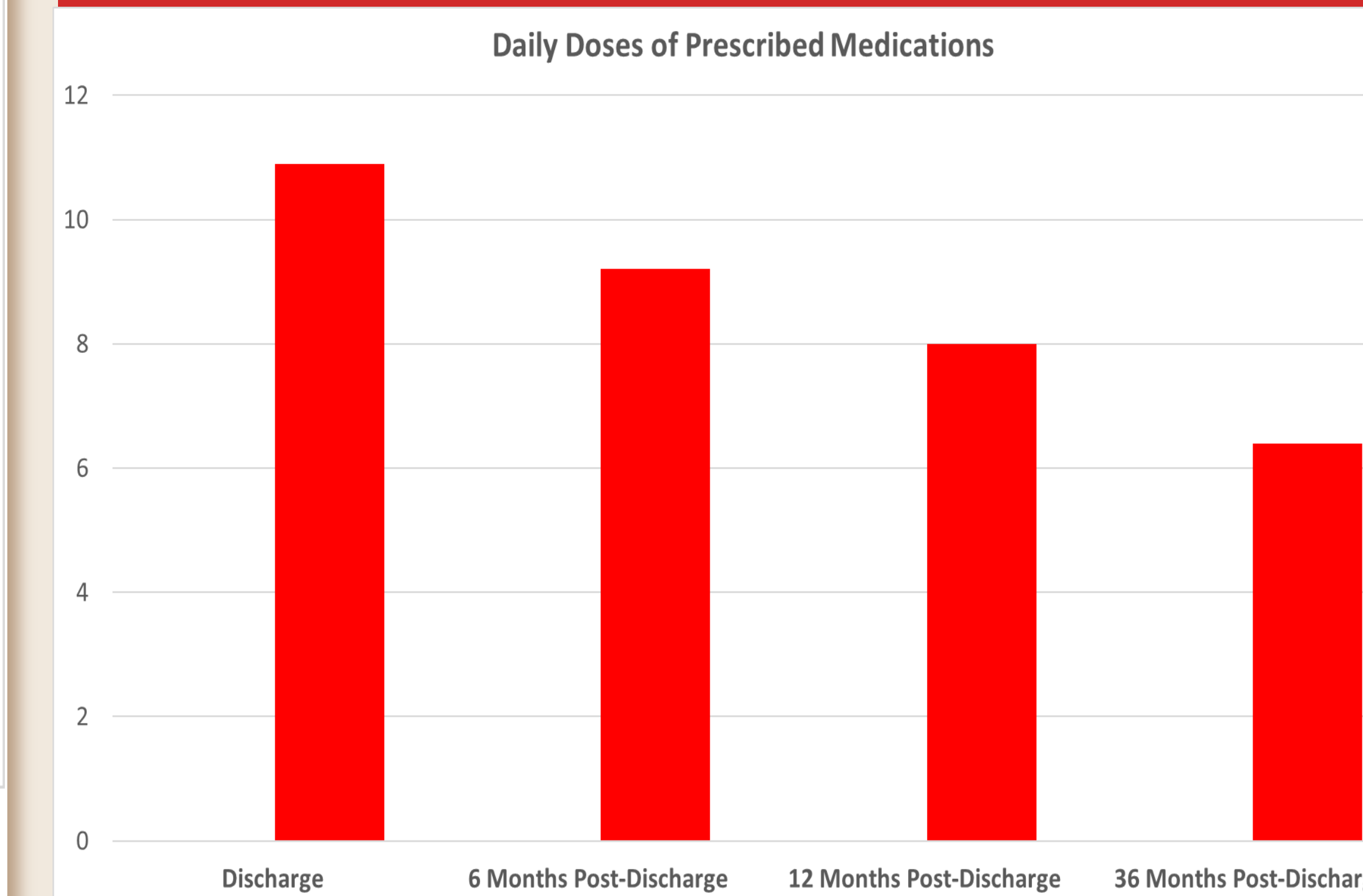
- Have significant burdens of medical care in the first 3 years after discharge
- Spend an average of 3 months hospitalized within the first year
- Encounter the need for frequent outpatient clinic visits
- Have significant non-cardiac medical needs
- Limitations: We did not track visits to non-specialty health care providers (PT, OT, Speech, Nutrition, PCP, ED visits)

## ADDITIONAL KEY INFORMATION

### Resources:

Landolt MA, Valsangiacomo Buechel ER, Latal B. Health-related quality of life in children and adolescents after open-heart surgery. J Pediatr 2008; 152: 349–55.

## Medications



- Average of 7.9 medications at discharge, with 10.9 daily doses