

# ASSESSMENT OF NEED FOR QUALITY IMPROVEMENT IN TRANSITIONAL CARE

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## BACKGROUND

- As pediatric heart transplant recipients age, there is inevitable need to eventually transfer their care to adult providers.
- Across other solid organ transplant populations, this shift from a family-centered to an individual-centered healthcare model is a vulnerable time period that is associated with adverse health outcomes with increased rates of graft loss and mortality.
- A formal transition program may better prepare patients for this transfer of care, however, this is a time and resource intensive endeavor for many programs.

## OBJECTIVE

- To examine our center's current practices in planning for transition of care, assessing transition readiness, and evaluating how medical treatment responsibility is allocated between patient and parent
  - To describe our pediatric heart transplant population's current transition readiness in terms of medical knowledge, engagement in health-related self-management skills, and family psychosocial functioning
- This needs assessment will inform the development of a formal transition program within our pediatric heart transplant program.

## METHODS

- Single center retrospective study
- Eligible patients included those >12 years of age and >2 years post-heart transplant who received routine follow-up care in our multidisciplinary transplant clinic
- Psychosocial risk was also evaluated using the Psychosocial Assessment Tool, a parent-reported psychosocial screening measure.
- Documentation by the medical providers, transplant psychologist and social workers were reviewed for the following components:
  - Transition Plan
  - Assessment of transition readiness
  - Assessment of allocation of responsibilities between patient and parent

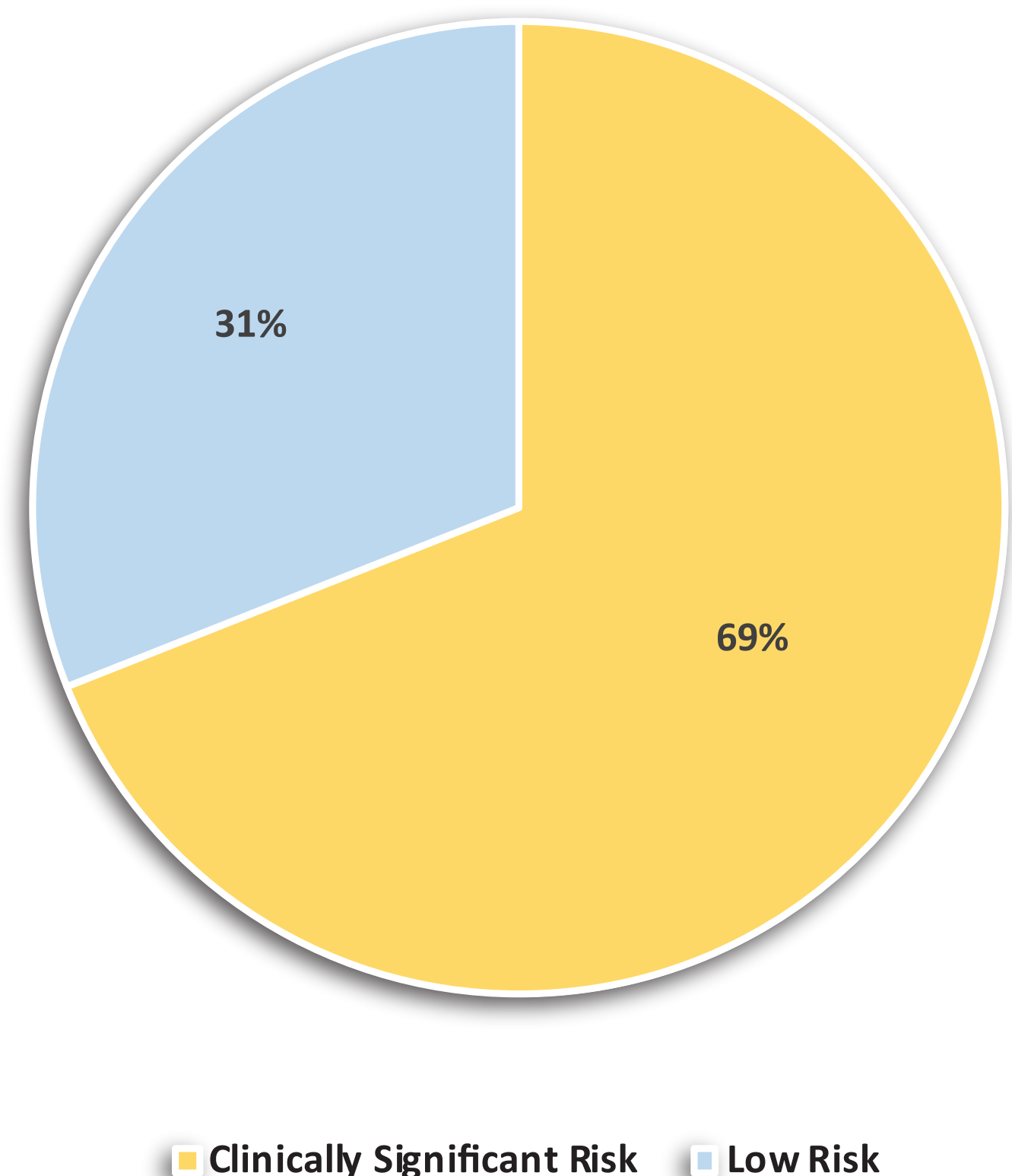
## RESULTS

- A total of 29 patients were included
- Patient age range 12-23 years

**Table 1: Components of Transition**

Total Number of Patients	N=29
<b>Rates of Documentation by Medical Providers</b>	
Provider documented a plan for transition/transfer of care in the medical records	10%
Providers documented that they assessed for one or more components of transition readiness.	55%
<b>Patient Self-Management</b>	
Patient responsible for medication management	20%
Patient responsible for medication administration	34.5%
Patient responsible for refilling medications	7%
Patient responsible for making appointments/contacting the medical team	14%
<b>Patient Knowledge</b>	
Patient has knowledge of the medical condition that led to transplant	52%
Patient understands why they take medications and the consequences	49%
Patient is aware of how their medical condition can impact their reproductive health	7%
Patient has knowledge regarding their insurance coverage	21%

**Figure 1: Patient and Familial Psychosocial Risk using the Psychosocial Assessment Tool**



## CONCLUSIONS

- A large portion of adolescents and young adults who are post-heart transplant continue to rely heavily on parental support to manage their healthcare.
- Improvements in provider documentation regarding transition planning are needed.
- Intensive efforts are needed in order to educate and prepare adolescents and young adults for transfer of care to adult providers.
- There is evidence for increased psychosocial risks in this vulnerable patient population, which may also impact transition outcomes.
- Future strategies must be developed by the multidisciplinary team to facilitate the shifting of responsibilities from the parents to the patient in preparations for a healthy transfer of care to an adult transplant program.

## FUTURE DIRECTIONS

- Implement a pilot multidisciplinary transitional care program for adolescent heart transplant patients that will:
  - Assess the transition needs of each individual patient
  - Improve provider documentation for a formal transition plan
  - Aim at addressing deficits in medical knowledge for each patient
  - Aim at providing patients and their families strategies to slowly shift responsibilities of managing health care from the parents to the patient

## DISCLOSURES

The authors have no financial disclosures or industry relationships to report.

## LIMITATIONS

This is a single center experience with a small study population and so the results are not generalizable to other programs.