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2-2015

Knowledge Gap in Adolescent Heart Transplant Recipients

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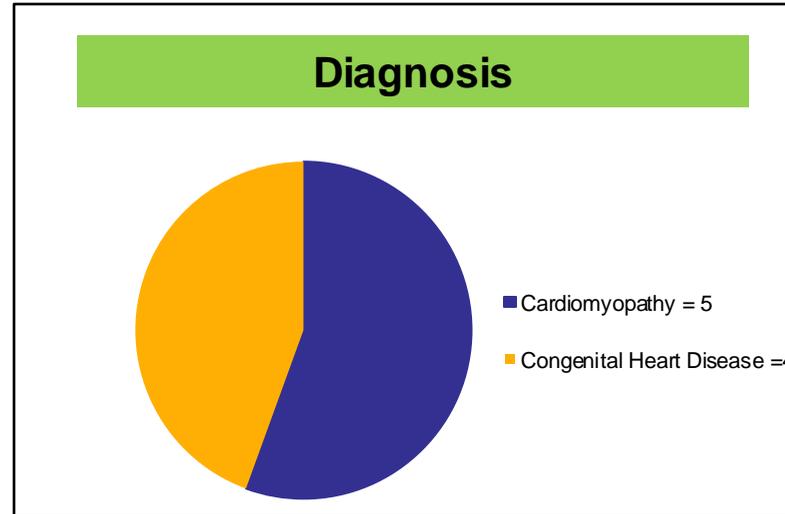
Children's Mercy Kansas City, Kansas City, Mo.

Background

- Studies have reported a knowledge gap among adolescent and young adult heart transplant patients upon transitioning to adult cardiology practices.
- This population is vulnerable to life-threatening complications as they progress to adult care.

Framework/Methods

- We assess the current knowledge deficit of our adolescent and young adult patients and their caregivers in order to inform pediatric providers of their unique needs as they prepare to transition.
- Heart transplant patients >10 yrs and their caregivers completed a written questionnaire prior to a clinic visit. 17 questions were asked including the need for transplant, medication names, purposes and adverse effects and the effects of living with a transplanted heart on exercise and work choices.
- Patients were all transplanted in another facility and initial education occurred at that facility.



Age at time of transplant: 0-14 years old, mean 9.7 years

Age at time of survey: 11-20 years old, mean 16.1 years

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Financial Disclosures:

All authors report no disclosures.

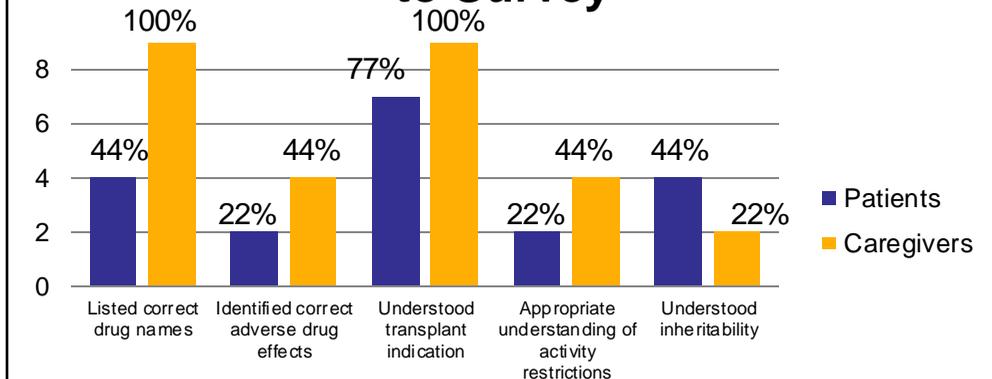
References:

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Results

Patient and Caregiver Responses to Survey



Conclusions

- Genetic factors and exercise/work limitations were the most misunderstood.
- Our patients and caregivers also lacked a clear understanding of medications and common and/or serious adverse effects.
- Areas that were well understood included: why the transplant was needed, meaning of immunosuppression, and the need for lifelong follow-up.
- Recently our facility was granted permission to perform heart transplants and it will be our responsibility to initially and fully educate the patient and caregivers. A comprehensive team including a pharmacist, dietician, genetic counselor, and psychologist, in addition to nurses and physicians has been formed and they will be knowledgeable of ongoing needs with the intent to close the knowledge gap.

Patient and Caregiver Responses to Survey

