Knowledge Gap in Adolescent Heart Transplant Recipients

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Knowledge Gap in Adolescent Heart Transplant Recipients

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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.

Results

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Cardiomyopathy = 5</th>
<th>Congenital Heart Disease = 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at time of transplant: 0-14 years old, mean 9.7 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at time of survey: 11-20 years old, mean 16.1 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient and Caregiver Responses to Survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listed correct drug names</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Identified correct adverse drug effects</td>
<td>44%</td>
<td>44%</td>
</tr>
<tr>
<td>Understood transplant indication</td>
<td>77%</td>
<td>77%</td>
</tr>
<tr>
<td>Appropriate understanding of activity restrictions</td>
<td>44%</td>
<td>44%</td>
</tr>
<tr>
<td>Understood inheritability</td>
<td>22%</td>
<td>22%</td>
</tr>
</tbody>
</table>

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.

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All authors report no disclosures.

References:
Patient and Caregiver Responses to Survey

- Listed correct drug names: 100% for Patients, 22% for Caregivers
- Identified correct adverse drug effects: 44% for Patients, 22% for Caregivers
- Understood transplant indication: 100% for Patients, 77% for Caregivers
- Self-imposed activity restriction: 77% for Patients, 66% for Caregivers
- Understood inheritability: 44% for Patients, 22% for Caregivers