Formal transition program may increase transition readiness, independence and self-confidence in young adults living with congenital heart disease: a prospective cohort

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**BACKGROUND**

Congenital Heart Disease (CHD) is the most common birth defect in the U.S.\(^\text{15}\)
- 1 million children & 1.4 million adults live with CHD in U.S.\(^\text{15}\)
- Literature shows first gap in care occurs at age 19\(^\text{1}\)

There is a lack in formal transition from pediatric to adult cardiology care.\(^\text{2, 6, 7, 11}\)

**CLINICAL QUESTION**

Will a formal transition program increase transition readiness, knowledge of disease process, and adult cardiology compliance among adolescents and young adults with congenital heart disease?

**METHODS**

Prospective non-randomized interventional study

Intervention ‘NP group’: 16-25 year old CHD patients who attend their ACHD nurse practitioner-led transition visit at pediatric cardiology
- Survey before visit → NP transition visit → Repeat survey
- Final survey given at first ACHD appointment

Control ‘MD only group’: 16-25 year old CHD patients transferred to adult cardiology without a transition visit
- Survey given to new patient at initial ACHD adult cardiology appointment prior to meeting physician

**STUDY DESIGN & DEMOGRAPHICS**

**TOOLS**

**47-Question Red Cap survey:** 4 demographics questions, 4 readiness assessment questions, MyHeart scale, and Transition Readiness Assessment Questionnaire (TRAQ)\(^\text{2, 14}\)

**Transition Visit Curriculum:** (use of ACHA My Health Passport\(^\text{2}\))
- Understanding of unique cardiac anatomy
- The importance of long-term cardiac care
- Notifying cardiologist of concerns or symptoms
- Taking medications as directed
- General information about birth control & pregnancy
- Lifestyle choices and exercise
- Adult cardiovascular risk
- Insurance coverage and Employment counseling

**RESULTS**

At baseline, no statistical difference was found between groups for CHD knowledge, transition readiness, independence or confidence

<table>
<thead>
<tr>
<th>Medical Knowledge Questions &amp; Transition Readiness</th>
<th>’MD only group’ Pre-transition N= 17</th>
<th>’NP group’ Post transition visit N= 14</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total % correct out of 16 knowledge questions</td>
<td>79%</td>
<td>78%</td>
<td>N.S.</td>
</tr>
<tr>
<td>Completed survey alone</td>
<td>71%</td>
<td>100%</td>
<td>0.05</td>
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<tr>
<td>Ready to manage health (score &gt; 3)</td>
<td>29%</td>
<td>77%</td>
<td>0.03</td>
</tr>
<tr>
<td>Confidence to explain heart defect</td>
<td>59%</td>
<td>93%</td>
<td>0.03</td>
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</table>

<table>
<thead>
<tr>
<th>Medical Knowledge Questions &amp; Transition Readiness</th>
<th>’NP group’ Pre-transition N= 14</th>
<th>’NP group’ 1st ACHD visit after transition N= 11</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total % correct out of 16 knowledge questions</td>
<td>69%</td>
<td>75%</td>
<td>0.02</td>
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<tr>
<td>Completed survey alone</td>
<td>79%</td>
<td>100%</td>
<td>0.01</td>
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<tr>
<td>Confidence to explain heart defect</td>
<td>43%</td>
<td>64%</td>
<td>0.01</td>
</tr>
</tbody>
</table>

**CONCLUSION**

- Nurse-led transition visit can be clinical & research focused
- A transition program for CHD patients transitioning to adult cardiology care is associated with:
  - Increased knowledge level and transition readiness
  - Enhanced level of independence and confidence
- Data collection is on-going to determine the retention of knowledge over time