**BACKGROUND**

**Congenital Heart Disease (CHD) is the most common birth defect in the U.S.**
- CHD is a lifelong condition and >85% of children with CHD now survive into adulthood

**Transition:**
- The purposeful, planned movement of adolescents & young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems
- Data suggests that first gap in care occurs at age 19
- Patients who have gaps in care have worse outcomes

**Review of the Literature:**
- 124 articles assess health personnel perspectives on transition from pediatric to adult care
- 16 articles highlight value of nurses in transition
- 0 studies assess nursing perspectives about transition and the role nurses are willing to play in this process
- Gap in the Literature exists

**AIM OF STUDY**
Identify nursing practice and beliefs regarding the need for and development of nursing interventions to assist youth with CHD in their transition from pediatric to adult cardiology care.

**METHODS**

**Vanderbilt IRB approved descriptive study**
- 18 question survey distributed to cohort of pediatric & adult, outpatient & inpatient cardiology nurses at Vanderbilt
- Survey included questions in the following categories:
  - Work role demographics
  - Perspectives on importance, timing & roles of transition
  - Current nursing practice for CHD patients
  - Perceived barriers to transition
  - Current transition involvement
  - Views on ideal transition interventions
- Data is presented as frequencies and percentages

**RESULTS**

693 eligible participants; 196 responded (28% response rate)

**Work role demographics:**
- 97% RNs (n=189); 3% LPNs (n=6)
- 59% inpatient cardiology nurses (n=115), 84% adult nurses (n=164), 28% pediatric nurses (n=55)
- 61% have not or are unsure if they have cared for a patient who transferred from pediatric to adult cardiology (n=110)

**Perspectives on importance, timing, and roles of transition:**
- 100% agree transition of care is important (n=195)
- 90% feel appropriate age is 13-20 years (n=174)
- 75% of participants feel their current role can play a part in the success of a patient’s transition (n=146)

<table>
<thead>
<tr>
<th>Who should be involved with transition?</th>
<th>% response</th>
<th>n count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric cardiology provider</td>
<td>96%</td>
<td>188</td>
</tr>
<tr>
<td>Adult cardiology provider</td>
<td>96%</td>
<td>187</td>
</tr>
<tr>
<td>Primary care provider</td>
<td>64%</td>
<td>125</td>
</tr>
<tr>
<td>Inpatient peds cardiology nurse</td>
<td>62%</td>
<td>121</td>
</tr>
<tr>
<td>Outpatient peds cardiology nurse</td>
<td>71%</td>
<td>138</td>
</tr>
<tr>
<td>Inpatient adult cardiology nurse</td>
<td>57%</td>
<td>112</td>
</tr>
<tr>
<td>Outpatient adult cardiology nurse</td>
<td>66%</td>
<td>129</td>
</tr>
<tr>
<td>Vanderbilt family resource center</td>
<td>52%</td>
<td>102</td>
</tr>
<tr>
<td>Child life specialist</td>
<td>61%</td>
<td>119</td>
</tr>
<tr>
<td>Social worker</td>
<td>70%</td>
<td>137</td>
</tr>
</tbody>
</table>

**Current nursing practice for CHD patients:**
- Topics covered: medication (72%), diagnosis (65%), when to contact provider (66%), birth control/pregnancy (16%), substance use (26%), self management (i.e. education, insurance, job) (35%)
- Resources used: Educational handout (41%), social worker (32%), child life (32%), none of the 9 options listed (36%)
- Limited nursing use of website/mobile app (23%)

**Perceived barriers to transition:**
- Unaware of current transition program (68%), Absence of transition protocol or insufficient training (55%), Hesitation to end long-term relationship with pediatric provider (54%)

**RESULTS (continued...)**

**Current transition involvement:**
- 86% of participants were previously unaware of Vanderbilt’s ACHD transition program (n=152)
- 61% (of 69 nurses who have cared for a CHD patient who transferred to adult care) noted the patient was unprepared for transfer (n=42)

**Views on ideal transition interventions:**
- Topics to review: Importance of long term care (73%), personal responsibility (74%), taking medications (59%)
- Educational measures nurses will use: one on one teaching (79%), pamphlet/hand-out (58%), referral to formal transition program or coordinator (59%)

**DISCUSSION**

- All participants agree smooth transition of care is important for positive health outcomes in patients with CHD
- Majority of participants agree their current nursing role can be involved in transition
- Nurses identify transition as a multi-disciplinary process involving both pediatric and adult caregivers which should begin at age 13-20 years
- Nurses feel insufficiently trained to address transition of care and note both a lack in transition protocol and awareness of resources
- Few nurses currently teach CHD patients about self management or lifestyle topics including substance use and family planning
- Mobile technology or online resources are underutilized by nurses in this young adult population

**CONCLUSION**

Cardiology nurses value an intentional transition of care for patients with congenital heart disease, but note a limited understanding of their role in this process and resources that exist.

*References available upon request*