Taking the Reins:
Transition Visits in Congenital Heart Disease

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Disclosure Statement

• We do not have any conflict of interest, nor will I be discussing any off-label product use
• This class has no commercial support or sponsorship, nor is it co-sponsored
Learning Objectives

• Review intent and goals of transition visits for pediatric congenital heart disease patients.

• Summarize research on transition of care from pediatric to adult congenital heart disease (ACHD) clinics.

• Summarize transition visits, current practices and national trends, known challenges, and future goals for congenital heart disease transition programs.
Congenital Heart Disease – It’s Not Just About Unusual A&P

• Roughly 1 in 100, most common birth defect in US.

• Affects the whole family, parents / guardians “have all the facts” during infancy and into early adulthood.

• Complex lesions often require multiple interventions (transcatheter or surgical) over a lifetime. Multi-disciplinary approach to care required – within and beyond cardiology -- interventional, surgical, electrophysiology, primary care, mental health professionals, hepatology, pulmonology.
Then...And Now

1950s
- 20% of infants with moderate to complex congenital heart disease (CHD) survived their first year.

Now
- ~90% of these patients now live into adulthood (US population).
- Lower survivability in certain countries with lower access to care.
2018 Guidelines

Improved outcomes with consistent, regularly scheduled, age-appropriate care.

As providers, we should ensure access to appropriate care from adolescence into adulthood.
The American Academy of Pediatrics states, “The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”
Transition Programs in the Literature...

AHA Scientific Statement

Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues

A Scientific Statement From the American Heart Association

Craig Sable, MD, FAHA, Co-Chair; Elyse Foster, MD, FAHA, Co-Chair; Karen Uzark, PhD, PNP, FAHA, Co-Chair; Katherine Bjornden, BSN, ARNP; Mary M. Canobbio, RN, MN, FAHA; Heidi M. Connolly, MD; Thomas P. Graham, MD, FAHA; Michelle Z. Gurvitz, MD, MS; Adrienne Kovacs, PhD, CPsych; Allison K. Meadows, MD, PhD; Graham J. Reid, PhD, CPsych; John G. Reiss, PhD; Kenneth N. Rosenbaum, MD; Paul J. Sagerman, MD, MS; Arwa Saidi, MB, BCh; Rhonda Schonberg, MS; Saneeeta Shah, MD; Elizabeth Tong, MS, RN, CPNP, FAHA; Roberta G. Williams, MD, FAHA; on behalf of the American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease

Original Investigation

Transition Intervention for Adolescents With Congenital Heart Disease

Andrew S. Mackie MD, SM a, b, A, B, Gwen R. Rempel RN, PhD a, 5, Adrienne H. K b, 7, Kathryn N. Rankin PhD a, Alexei Jelen BA Hons a, Maryna Vaskina PhD a, Ren MD a, Dimi Dragieva RN a, Sonila Mustafa RN a, Elina Williams RN a, Michelle Sc Samantha J. Anthony PhD a, MSW a, Joyce Magill-Evans PhD a, David Nicholas Phi a, 7

Clinical Research

Estimates of Life Expectancy by Adolescents and Young Adults With Congenital Heart Disease

Graham J. Reid PhD a, 7, 1, R, 2, 5, Gary D. Webb MD 3, #, Mor Barzel MA *, Brian W. McCrinkle MD **, M. Jane Irvine PhD #, **, Samuel C. Siu MD #, *
How Are We Doing Now?

- Current research suggests we have a lot of work to do.

- Limited data at national level that is specific to congenital heart disease.
  - No studies yet published comparing how transition visits done between ACHA-approved centers.

- Lapses in care are common, but should not be the norm: "...21 to 76% of adolescents and young adults have a lapse in cardiology care." (Downing, et al).
Follow Developmental Cues – Transition Timeline

By age 12 – 14 – encourage the patient to try having a portion of annual visit alone with their provider. Assess level of understanding as to congenital heart anatomy, implications.

Age 14: Start discussing process of transition to adult care.

Teen begins to practice tracking own appointments.
• Gaps in care leads to increased hospitalizations, urgent interventions, higher morbidity.
  • Lack of routine follow ups / diagnostic testing.

• Starting the conversation earlier reduces risk of gaps in care.
Without Transition Visits...

• Patients miss their routine follow up visits.
  • Absence of ACHD specific care
• Patient may not feel comfortable / informed to explain their own cardiac anatomy / interventions.
• Lack of eye contact with the provider, patient actually looks to a family member to provide information.
  • Follow the historic pattern

• Big / tough questions may not get addressed:
  • Prognosis, family planning, risky behaviors, self-care)
What We Can Avoid...
Primary Goals of Transition Visits

• The patient takes charge, increases self-awareness of their cardiac anatomy, historic interventions, and strengthens their self-advocacy skills.
• Provide practice engaging with provider directly, asking hard questions
• Assess readiness of the patient & family
• Reduce anxiety about transferring away from Seattle Children’s
• Educate the patient & family about the care model at the University of Washington
• Discuss healthy lifestyle habits & risky behaviors
I started tracking patients when I began working with the ACHD providers in October 2015.

Since then, about 427 patients were transitioned to the UW Medical Center Adult Congenital Heart Program (as of December 2019).

Of the 427 patients, 306 had a transition visit.
SCH Transition Visits

• There are two Adult Congenital RNs at Seattle Children’s – Sophia Sauer and Sully Sullivan

• The patients general cardiologist begins the process by placing a consult order for one of the ACHD providers.

• The schedulers call out on the consults orders and the RNs assist with the logistics.
Three Transition Visits Throughout Adolescents:

• Initial transition visit occurs between 14 or 15 years of age

• Second transition visit 2 years after the initial visit between 16-18 years of age

• Third transition visit done closer to last visit with the primary cardiologist at 20-21 years of age
# SCH Transition Visits

<table>
<thead>
<tr>
<th>Name</th>
<th>Patient’s Phone Number:</th>
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<tbody>
<tr>
<td>MRN</td>
<td></td>
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<tr>
<td>Primary Cardiac Diagnosis</td>
<td></td>
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<tr>
<td>Additional Diagnosis or Services (That need to be transferred to UWMC ex: Anticoagulation, EP/Devices, Developmental Issues, CASPER or Social Work Issues)</td>
<td></td>
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<tr>
<td>Timeframe for Visit</td>
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<tr>
<td>Testing Needed with Visit</td>
<td></td>
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<tr>
<td>Referring Provider</td>
<td></td>
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<tr>
<td>Identified ACHD Provider (if one has been identified)</td>
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</tbody>
</table>
Looking Ahead / Future Goals

- ARNP/RN led transition visits
- ACHD providers travel to regional clinics to provide transition visit vs. telemedicine visits
Systemic Challenges

• Scheduling the necessary transition visits can be a burden to patients and families

• Transition visits aren’t offered everyday of the week

• Insurance coverage can be different between SCH and UWMC, changes to insurance plan coverage from year to year
In Summary

• Transition program visits help empower congenital heart disease patients to take the reins, self-advocate and direct their own care.

• National data is lacking but we do know that with adequate transition visits we reduce ED visits, urgent interventions and improve overall outcomes.

• Start the conversation earlier than later
References

- Stout, KK et al, JACC, 2018: "AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease" http://www.onlinejacc.org/content/73/12/e81?_ga=2.198387119.1603272812.1586800857-226041656.1586800857
- CDC on Congenital Heart Disease: https://www.cdc.gov/ncbddd/heartdefects/data.html
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Dr. Jason Deen, Dr. Jill Steiner and the UW/SCH ACHD Team