



Nursing perspectives on the transition to adulthood for adolescent and young adult patients with congenital heart disease

Gretchen Jayawardena BAN RN; Angela Weingarten MD, MSCI;
Rachel Kromer, MSN, RN-BC, NP-C; & Elizabeth Card MSN APRN FNP-BC

BACKGROUND

Congenital Heart Disease (CHD) is the most common birth defect in the U.S. ²⁴

- 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^{1, 8,21,22}
- Data suggests that first gap in care occurs at age 19¹⁸
- Patients who have gaps in care have worse outcomes¹⁸

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 ¹⁻¹⁶
- 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)

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

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