



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. ¹⁵

- 1 million children & 1.4 million adults live with CHD in U.S. ¹⁵
- Literature shows first gap in care occurs at age 19 ¹

There is a lack in formal transition from pediatric to adult cardiology care. ^{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

	Consent & Enroll	Survey	Transition NP visit	Survey (after NP)	Survey
'MD only group'	✓	✓ ACHD			
'NP group'	✓	✓	✓	✓	✓ ACHD

- Numeric data organized via Mann-Whitney Test, Pearson Chi-Square Test, Wilcoxon Signed Ranks Test, and McNemar Test

*References and Survey available upon request

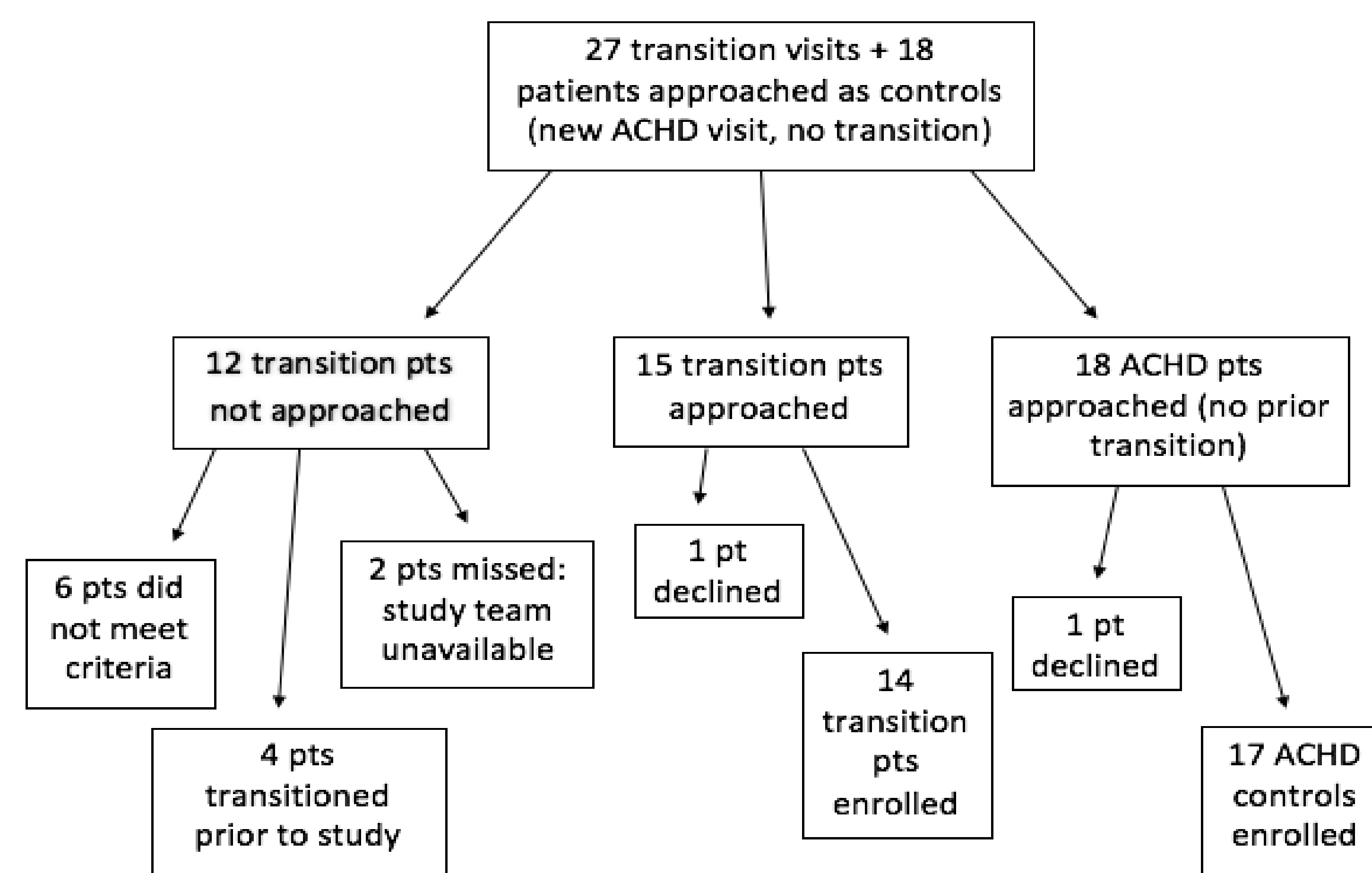
TOOLS

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

Transition Visit Curriculum: (use of ACHA My Health Passport²)

- 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

STUDY DESIGN & DEMOGRAPHICS



Demographic	'MD only group' No transition visit N= 17	'NP group' Transition visit N= 14	P value
Age	20.5 years	19.4 years	N.S.
% Female	24%	42%	N.S.
% Caucasian	88%	93%	N.S.
Post-secondary education	47%	50%	N.S.

RESULTS

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

Medical Knowledge Questions & Transition Readiness	'MD only group' No transition N= 17	'NP group' Post transition visit N = 14	P value
Total % correct out of 16 knowledge questions	79%	78%	N.S.
Completed survey alone	71%	100%	0.05
Ready to manage health (score > 3)	29%	77%	0.03
Confidence to explain heart defect	59%	93%	0.03

Medical Knowledge Questions & Transition Readiness	'NP group' Pre-transition N= 14	'NP group' Post transition N= 14	P value
Total % correct out of 16 knowledge questions	69%	78%	0.02
Completed survey alone	79%	100%	0.01
Confidence to explain heart defect	43%	93%	0.02

Medical Knowledge Questions & Transition Readiness	'NP group' Pre transition visit N= 14	'NP group' 1st ACHD visit after transition N = 11	P value
Total % correct out of 16 knowledge questions	69%	75%	0.02
Completed survey alone	79%	100%	0.046
Confidence to explain heart defect	43%	64%	0.01

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