



# Healthcare Responsibilities and Transition Readiness in Adolescent Solid Organ Transplant Recipients

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### Introduction

- Given increased survivorship following solid organ transplantation, there are more adolescents and young adults (AYAs) preparing to transition from pediatric to adult healthcare.
- AYAs must navigate unfamiliar roles and environments while increasing self-efficacy and drawing on emerging abilities to organize and plan.<sup>1</sup>
- It is recommended that responsibility for healthcare tasks be attained prior to transfer, and preparation for transition begin early.<sup>2</sup>
- This study examined the specific attained responsibilities among AYA solid organ transplant recipients that distinguishes those who are more ready to transition to adult healthcare.

# Methods

- Participants
- 65 heart, kidney, or liver transplant recipients aged 12-21, and their caregivers.
- Measures
- Readiness for Transition Questionnaire (RTQ)<sup>3</sup>
  AYA-report of their readiness for transition and their own responsibility for healthcare tasks
- Readiness for transition: Likert Scale (1, Not at all ready 4, Completely ready)
- Responsibility for healthcare tasks: Likert Scale (1, Not at all 4, Completely)
- Behavior Rating of Executive Functioning Skills (BRIEF)<sup>4</sup> Caregiver-reported AYA Executive functioning (EF) skills

# Analyses

• ANCOVA controlling for AYA age and EF examined which healthcare tasks distinguish between AYAs with high or low perceived transition readiness.

#### Results

Increased competency in more **managerial healthcare tasks** (e.g., scheduling, insurance) = **greater transition readiness**, as compared to
routine healthcare tasks (e.g., labs, medications).

# Sample Demographics (N=65)

M(SD)

AYA Age (years)	16.64(1.80)					
Years since transplant	8.06(5.61)					
	N(%)					
Organ group						
Kidney	23 (25.4%)					
Liver	24 (36.9%)					
Heart	18 (27.7%)					
Child Gender						
Male	39 (60%)					
Female	26 (40%)					
Child Race/Ethnicity						
White	35 (53.8%)					
Black	19 (29.2%)					
Hispanic	3 (4.6%)					

Asian 3 (4.6%)

Biracial 5 (7.7%)

\$0-\$9,999 3 (4.6%)

\$10,000-\$24,999 10 (15.4%)

\$25,000-\$49,999 18 (27.7%)

\$50,000-\$74,999 11 (16.9%)

\$75,000-\$99,999 6 (9.2%)

\$100,000 or greater 16 (24.6%)

Not provided 1 (1.5%)

**Family Income** 

# ANOVA and Chi Square: Readiness for transition and demographic and EF variables

	All	Not at all/ Somewhat ready	Mostly/ Completely ready	
	Mean(SD)/N(%)	Mean(SD)/n(%)	Mean(SD)/n(%)	$F/X^2$
	(N=65)	(n=38)	(n=27)	
Age (years)	16.64(1.80)	16.11(1.73)	17.38(1.64)	8.88**
Time since tx (years)	7.95(5.67)	7.71(5.42)	8.31(6.11)	0.17
Gender (male)	39(60%)	22(58%)	17(63%)	0.17
BRIEF GEC (T-score)	53.95(11.62)	57.50(11.92)	48.96(9.26)	9.67**

# ANCOVA:

# Readiness for transition and level of responsibility for healthcare tasks

Readiness for Transition	All	Not at all/ Somewhat ready	Mostly/ Completely ready	
	Mean(SD)	Mean(SD)	Mean(SD)	<i>F</i> , <i>p</i>
	(N=65)	(n=38)	(n=27)	
Getting monthly labs	2.75(1.09)	2.50 (1.01)	3.11(1.12)	3.06
Taking medication daily	3.62(0.60)	3.61(0.59)	3.63(0.63)	0.01
Scheduling specialty appts	2.29(1.18)	1.95(1.14)	2.78(1.09)	5.90*
Scheduling primary appts	2.18(1.21)	1.84(1.07)	2.67(1.24)	4.86*
Calling in order refills	2.45(1.29)	2.11(1.20)	2.93(1.27)	4.93*
Explaining condition	3.28(0.99)	3.13(0.99)	3.48(0.98)	0.77
<b>Knowing insurance details</b>	2.02(1.08)	1.61(0.89)	2.59(1.08)	11.42***
Attending appointments	3.32(1.06)	3.21(1.12)	3.48(0.98)	0.69
Communicating in person	3.45(0.88)	3.39(0.86)	3.52(0.94)	0.25
Communicating via phone	2.52(1.29)	2.16(1.24)	3.04(1.19)	2.39

*Note*. ANCOVA controlling for AYA age and EF. \* p < .05, \*\* p < .01, \*\*\* p < .001

### Discussion

- AYAs who reported being mostly or completely ready for transition also report greater competency in the more complex logistical healthcare tasks, including knowing insurance, appointment scheduling, and ordering refills.
- Participants who were high or low in overall transition readiness did not differ on the more routine tasks of daily medication taking, getting labs, or communicating about their condition.
- All AYAs should be competent in these routine healthcare management skills, as these skills are foundational. However, increasing competencies in more complex healthcare tasks distinguishes AYAs with greater perceived transition readiness and self-efficacy in managing their own healthcare, even after controlling for age and EF.

#### **Future Directions**

- Specific attention should be given to developing greater AYA responsibility for complex healthcare tasks in preparing AYAs for transition and transfer.
- Transition interventions should focus on these complex healthcare tasks as areas to improve AYA transition preparation.

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<sup>1</sup>Reed-Knight, B., Blount, R. L., & Gilleland, J. (2014). The transition of health care responsibility from parents to youth diagnosed with chronic illness: A developmental systems perspective. Families, Systems, & Health, 32(2), 219.

<sup>2</sup> Bell, L. E., Bartosh, S. M., Davis, C. L., Dobbels, F., Al-Uzri, A., Lotstein, D., ... & conference attendees. (2008). Adolescent transition to adult care in solid organ transplantation: a consensus conference report. American Journal of Transplantation, 8(11), 2230-2242.

<sup>3</sup> Gilleland, J., Amaral, S., Mee, L., & Blount, R. (2011). Getting ready to leave: transition readiness in adolescent kidney transplant recipients. Journal of Pediatric Psychology, 37(1), 85-96. doi: 10.1093/jpepsy/jsr049

<sup>4</sup> Gioia, G. A., Isquith, P. K., Guy, S. C., & Kenworthy, L. (2000). Test review behavior rating inventory of executive function. Child Neuropsychology, 6(3), 235-238.