Disagreement in Healthcare Responsibility Among Adolescent and Young Adult Solid Organ Transplant Recipients and Caregivers

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Introduction

- Given increased survivorship following solid organ transplantation, there are more adolescent and young adults (AYA) preparing to transition from pediatric to adult healthcare post-transplant.
- This often involves AYAs transferring healthcare responsibilities from caregivers to AYAs and learning to self-manage their care.
- The period of adolescence is a time of transition for both caregivers and AYAs, can result in discrepancies in perceptions of responsibility.[1]
- This study examines disagreements in reports of primary responsibility for healthcare tasks among AYA transplant recipients and caregivers, and how these disagreements relate to family functioning and medication adherence.

Methods

- Participants
  - 55 heart, kidney, or liver transplant recipients aged 12-21, and their caregivers.
- Measures
  - *Readiness for Transition Questionnaire (RTQ)*[2]
    - Yes/no, did AYAs and caregivers report same person primarily responsible for healthcare tasks
  - *Medication Adherence Measure (MAM)*[3]
    - Yes/no, did AYAs and caregivers report same person primarily responsible for medication tasks
  - *Family Adaptability and Cohesion Evaluation Scale (FACES)*[4] – Family cohesion and flexibility subscales
  - Medication adherence:
    - Caregiver and AYA-reported: *MAM*[3]
    - Anti-rejection drug assay levels (Adherent < 2 SD, Non-adherent ≥ 2 SD)

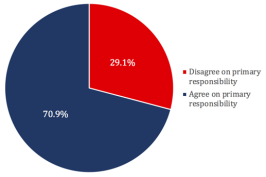
Analyses

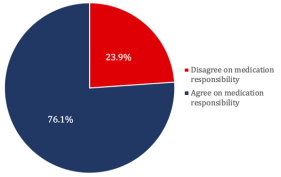
- Relations were examined using ANCOVA controlling for AYA age and time since transplant between dyads who agree/disagree on outcomes of family func. and adherence.
- Chi-Square tests examined the relationship between dyads who agree/disagree and who were determined to be adherent/nonadherent by drug assay values.

Results

Sample Demographics (N=55)

	M(SD)
AYA Age (years)	16.84(1.82)
Years since transplant	8.15(5.75)
	N(%)
Organ group	
Heart	18 (32.7)
Kidney	19 (34.5)
Liver	18 (32.7)
Child Race/Ethnicity	
White	26 (47.2)
Black	15 (27.3)
Hispanic	2 (3.6)
Asian	1 (1.8)
Biracial	3 (5.5)
Family Income	
$0-$9,999	3 (5.5)
$10,000-$24,999	7 (12.7)
$25,000-$49,999	14 (25.5)
$50,000-$74,999	10 (18.2)
$75,000-$99,999	5 (9.1)
$100,000 or greater	15 (27.3)



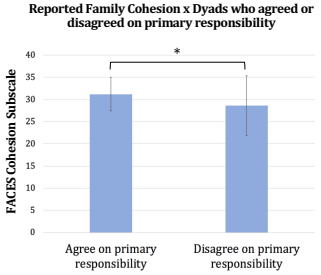


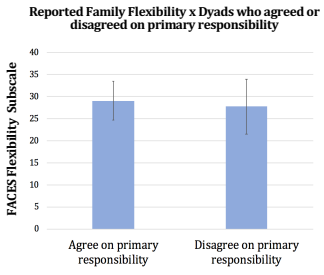
Outcome: Medication Adherence

	Agree on Prim Responsibility Mean (SD)	Disagree on Prim Responsibility Mean (SD)	*F*	Agree on Med Responsibility Mean (SD)	Disagree on Med Responsibility Mean (SD)	*F*
Caregiver-reported adherence						
% of AR Meds Missed	1.16 (7.05)	0.63 (2.46)	0.02	1.64 (7.10)	0.00 (0.00)	0.52
% of AR Meds Late	5.19 (10.19)	1.78 (4.91)	1.25	2.35 (6.52)	6.49 (11.27)	2.10
% of Other Rx Meds Missed	4.14 (12.88)	8.36 (18.51)	0.26	5.23 (14.72)	5.88 (15.56)	0.08
% of Other Rx Meds Late	2.35 (6.29)	1.24 (5.67)	0.00	0.60 (2.11)	2.04 (5.40)	1.04
% of non-Rx Meds Missed	12.70 (32.51)	3.57 (10.48)	0.47	7.76 (22.93)	14.29 (37.80)	0.14
% of non-Rx Meds Late	**0.35 (1.27)**	**3.33 (8.99)**	**5.50***	0.62 (1.64)	0.00 (0.00)	1.00
AYA-reported adherence						
% of AR Meds Missed	1.02 (3.37)	0.45 (1.79)	0.01	0.93 (3.18)	0.68 (2.55)	0.06
% of AR Meds Late	4.71 (10.04)	2.92 (5.69)	0.11	4.03 (9.68)	4.88 (7.15)	0.10
% of Other Rx Meds Missed	4.97 (12.01)	12.64 (20.23)	1.21	**5.22 (13.69)**	**15.35 (18.68)**	**4.03***
% of Other Rx Meds Late	1.43 (3.47)	2.23 (6.12)	1.19	1.13 (3.25)	3.75 (7.07)	2.30
% of non-Rx Meds Missed	8.47 (26.95)	15.71 (25.62)	0.02	10.20 (24.55)	12.50 (35.36)	0.03
% of non-Rx Meds Late	3.02 (8.82)	1.10 (2.73)	0.62	**1.07 (3.18)**	**7.81 (14.91)**	**5.79***

Note. There were no relations between responsibility agreement in Medication Level Variability Index (MLVI).

Outcome: Family Functioning





* $p < .05$, ** $p < .01$, *** $p < .001$

Discussion

- Almost one-third of dyads disagreed on who was primarily responsible for healthcare tasks.
- Dyads who disagreed about who was primarily responsible had significantly lower family cohesion than dyads who agreed, highlighting the importance of understanding perceived responsibility and transition in the context of current family dynamic.
- Notably, disagreement was not related to family flexibility, indicating something more complex than just lack of clearly defined roles.
- Disagreement was also associated with missed prescription medications and late non-prescription medication taking, indicating a need for providers to discuss the importance of adherence to the entire medication regimen, rather than selective adherence to anti-rejection medications, particularly during the crucial period of transition. Notably, there were no significant differences in MLVI.

Future Directions

- Future research should develop brief interventions aimed at increasing communication regarding responsibility in dyads and promoting effective transition.
- Future research should also examine the relationship between the direction of agreement and disagreement and how this may relate to family functioning and medical outcomes.

Acknowledgements & References

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