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, which 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 health care 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

- Relationships were examined using ANCOVA controlling for AYA age and time since transplant between dyads who agree/disagree on outcomes of family function 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

### Outcome: Medication Adherence

<table>
<thead>
<tr>
<th>Caregiver-reported adherence</th>
<th>Agree on Prim Responsibility</th>
<th>Disagree on Prim Responsibility</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of All Med Missed</td>
<td>1.14 (7.00)</td>
<td>6.30 (28.46)</td>
<td>0.02</td>
</tr>
<tr>
<td>% of AR Med Missed</td>
<td>5.10 (19.10)</td>
<td>2.76 (10.27)</td>
<td>1.25</td>
</tr>
<tr>
<td>% of Other Rx Meds Missed</td>
<td>4.14 (12.84)</td>
<td>6.06 (10.51)</td>
<td>0.26</td>
</tr>
<tr>
<td>% of Other Rx Meds Late</td>
<td>3.75 (7.29)</td>
<td>2.58 (24.57)</td>
<td>0.08</td>
</tr>
<tr>
<td>% of AR Meds Late</td>
<td>7.50 (16.31)</td>
<td>5.77 (10.46)</td>
<td>0.67</td>
</tr>
<tr>
<td>AYA-reported adherence</td>
<td>0.35 (1.27)</td>
<td>0.23 (0.99)</td>
<td>1.58*</td>
</tr>
</tbody>
</table>

### Outcome: Family Functioning

<table>
<thead>
<tr>
<th>Reported Family Cohesion &amp; Dyads who agreed or disagreed on primary responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reported Family Cohesion &amp; Dyads who agreed or disagreed on primary responsibility</td>
</tr>
<tr>
<td>Mean (SD)</td>
</tr>
</tbody>
</table>

### Family Income

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>$0-$49,999</td>
<td>3.70 (1.15)</td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>3.50 (1.32)</td>
</tr>
<tr>
<td>$100,000 or greater</td>
<td>3.30 (1.32)</td>
</tr>
</tbody>
</table>

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

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 cooperation.
- 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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