Transition planning and health literacy in teens with special health care needs

Deena J. Chisolm, PhD
Center for Innovation in Pediatric Practice
TeenLit team

- Deena Chisolm, PI
- Jessica Conn, Research Assistant
- Elizabeth Earley, Project Coordinator
- Kelly Kelleher, Physician Advisory Panel
- Garey Noritz, Physician Advisory Panel
- Lee Sanders, Physician Advisory Panel

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Children with Special Health Care Needs (CSHCN)

• Nearly a quarter of Ohio (23%) youths have chronic conditions requiring enhanced health-related services

• CSHCN are more likely to live in socio-economically disadvantaged families

• CSHCN are more likely to have unmet medical, dental, and prescription medication needs

Transition to adult care

- During transition families must prepare for changes in providers, disease management responsibility, insurance, and more
- Nationally, only 40% of parents received desired, comprehensive counseling on preparation for transition
- Communication is less likely to occur when children live in poverty, when they are publically insured or uninsured, and when they have more complex conditions
- Nothing is known about whether such communication is occurring with the youths directly or how parent and child health literacy are associated with transition communication

Source: www.childhealthdata.org
Teens with SHCN face special challenges in transition and transitions are failing

Source: 2012 OMAS preliminary data
The Big Question

How might health literacy play a role in effective transition planning?
Health literacy and Internet use

Intent to use recommended eHealth resources by health literacy score

Teen Literacy in Transition (TeenLIT) Specific aims

- Assess the relationship between adolescent health literacy, parent health literacy, and effective planning for the healthcare transition from adolescence to adulthood.

- Assess the relationship between adolescent health literacy, parent health literacy, and adolescent health indicators including health-related quality of life and healthcare utilization.

- Identify mediators and moderators of racial disparity in health literacy in a large, diverse Medicaid managed care population of adolescents with special health care needs.
Study population

- Initial Screening - Medicaid Claims data
  - Ages 15-18
  - Diagnosed with at least one of twenty diagnoses found in over 90 percent of CSHCN
  - Enrolled in Medicaid for 12 previous months

- Secondary screening - Telephone
  - Questionnaire for Identifying Children with Chronic health Conditions-Revised (QUICCC-R)
  - English proficiency
  - No significant developmental delay
  - Functional Limitation classification
Baseline data collection

• Health Literacy Assessment
  – REALM/REALM-Teen
  – Newest Vital Signs
  – Health Literacy Screening Items
  – eHEALS

• Tablet administered Red Cap questionnaire
  – Transition Readiness Assessment Questionnaire
  – NS-CSHCN Transition core indicators
  – eHealth Use (Adapted from Pew Internet Survey)
  – Quality of life and satisfaction with care (PedsQL)
Follow-up data collection

• Claims data for 12 months before and following interview date to assess
  – Well-care/Ambulatory visits
  – ED visits
  – Ambulatory care sensitive ED visits
  – Hospitalizations
  – Charges
### Participant characteristics (N=130)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Parent</th>
<th>Teen</th>
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</thead>
<tbody>
<tr>
<td><strong>Age Mean (range)</strong></td>
<td>30-40 years (40%)</td>
<td>17.2 years</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5 (3.9%)</td>
<td>64 (49.2%)</td>
</tr>
<tr>
<td>Female</td>
<td>125 (96.2%)</td>
<td>66 (50.8%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>80 (61.6%)</td>
<td>73 (56.2%)</td>
</tr>
<tr>
<td>Black</td>
<td>38 (29.2%)</td>
<td>40 (30.8%)</td>
</tr>
<tr>
<td>Other</td>
<td>12 (9.2%)</td>
<td>17 (13.1%)</td>
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<tr>
<td><strong>Level of Limitation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td>39 (30.0%)</td>
</tr>
<tr>
<td>Some</td>
<td></td>
<td>55 (42.3%)</td>
</tr>
<tr>
<td>Severe</td>
<td></td>
<td>36 (27.7%)</td>
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</tbody>
</table>
## Health literacy levels

<table>
<thead>
<tr>
<th></th>
<th>Parent</th>
<th>Teen</th>
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</thead>
<tbody>
<tr>
<td><strong>REALM/REALM-Teen</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate</td>
<td>106 (81.5%)</td>
<td>71 (54.6%)</td>
</tr>
<tr>
<td>Marginal</td>
<td>18 (13.9%)</td>
<td>49 (37.7%)</td>
</tr>
<tr>
<td>Inadequate</td>
<td>6 (4.6%)</td>
<td>9 (6.9%)</td>
</tr>
<tr>
<td><strong>NVS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate</td>
<td>76 (58.5%)</td>
<td>63 (48.5%)</td>
</tr>
<tr>
<td>Marginal</td>
<td>15 (11.5%)</td>
<td>53 (40.8%)</td>
</tr>
<tr>
<td>Inadequate</td>
<td>39 (30.0%)</td>
<td>14 (10.8%)</td>
</tr>
</tbody>
</table>
Trouble understanding written information (sometimes, often, always)

Confidence filling out forms (somewhat, a little bit, not at all)

Need help reading health materials (sometimes, often, always)
Teen health literacy and transition communication with teens

- Provider Transition
  - Adeq HL: 24%
  - LT Adq HL: 24%

- Health Changes
  - Adeq HL: 37%
  - LT Adq HL: 59%

- Insurance Changes
  - Adeq HL: 24%
  - LT Adq HL: 46%

Discussion

- Lack of need for discussion:
  - Provider Transition: 48%
  - Health Changes: 22%
  - Insurance Changes: 5%
Parental health literacy and transition communication with parents

- Provider Transition
  - Adeq HL: 27%
  - LT Adq HL: 5%

- Health Changes
  - Adeq HL: 33%
  - LT Adq HL: 10%

- Insurance Changes
  - Adeq HL: 12%
  - LT Adq HL: 7%
Conclusions

• Transition planning for teens with special health care needs is poor across health literacy levels
• Overall, teens report more transition communication than their parents
• Teens with lower health literacy were more likely to report communication regarding changing health and insurance needs
• Parents with lower literacy were less likely to report any communication regarding their child’s transition needs
• Recruitment is ongoing…More to come!!
Thank You!