Health Literacy in Teens with Special Health Care Needs

Deena Chisolm, PhD
Nationwide Children’s Hospital and The Ohio State University
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?
Teen Literacy in Transition (TeenLIT) Specific Aims

• Assess the relationship between adolescent health literacy, parent health literacy, and effective planning for the health care 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 health care 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. Relationships tested will include primary language spoken at home, rural/urban residence, and parental education.
Study population

• Initial Screening - Medicaid Claims data
  • Ages 15-17
  • 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
  • QuiCCC-R
  • English proficiency
  • No significant developmental delay
  • Functional limitation classification
Core Measures

• Rapid Evaluation of Adult Literacy in Medicine
• Newest Vital Sign
• The Brief items (Chew)
• E-HEALS Electronic Health
• Transition Core Indicator – NS-CSHCN
• Transition Readiness Assessment Questionnaire (TRAQ)
• Health care utilization (Medicaid Claims Data)
## Participant characteristics (N=591)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Parent</th>
<th>Teen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Mean (range)</td>
<td>30-40 years (43.1%)</td>
<td>16.8 years</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>32 (5.4%)</td>
<td>283 (47.9%)</td>
</tr>
<tr>
<td>Female</td>
<td>559 (94.6%)</td>
<td>308 (52.1%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>373 (63.1%)</td>
<td>340 (57.5%)</td>
</tr>
<tr>
<td>Black</td>
<td>175 (29.6%)</td>
<td>182 (30.8%)</td>
</tr>
<tr>
<td>Other</td>
<td>43 (7.3%)</td>
<td>69 (11.7%)</td>
</tr>
<tr>
<td>Level of Limitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td>150 (26.8%)</td>
</tr>
<tr>
<td>Some</td>
<td></td>
<td>249 (44.5%)</td>
</tr>
<tr>
<td>Severe</td>
<td></td>
<td>161 (28.8%)</td>
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</tbody>
</table>
Health literacy in teens with chronic illness

- Self-report: 66.5%
- REALM: 52.5%
- Newest Vital Sign: 39.6%
Linking Health Literacy and E-Health Literacy

- I know what health resources are available on the Internet: 51.5%
- I know how to use the internet to answer questions about my health: 83.0%
- I feel confident using information from the internet to make health decisions: 46.3%
- I have the skills I need to evaluate the health resources I find on the internet: 64.0%
Parent-Teen Health Literacy Concordance

REALM

Written Material

Numerical info

Concordant adq  |  parent only |  teen only |  concordant <adq

Disparity in Assessed Health Literacy

![Disparity in Assessed Health Literacy](image-url)
Disparities in Self-Reported Health Literacy

- Written Information: 76% AA, 75% NHW
- Medical Forms: 55% AA, 46% NHW
- Reading: 67% AA, 62% NHW
Transition Communication

Measure: Transition Core Indicator NSCHCN
Transition Readiness

Measure: The Transition Readiness Assessment Questionnaire (TRAQ)
Health Care Utilization

- Any ED Visit:
  - Adequate Self-Report HL: 43%
  - Below Adequate Self-Report HL: 56%

- Any Inpatient Stay:
  - Adequate Self-Report HL: 5%
  - Below Adequate Self-Report HL: 10%
Take Home Messages

• Teens with chronic illness are increasingly expected to actively engage in health management
• For some teens, health literacy limitations make that difficult
• Parents aren’t always the solution
• Health literacy is an important consideration for transition planning and education
Thank You!

The TeenLIT Team
Mary Ann Abrams
Johnna Booker
Laura Chavez
Jessica Conn
Millie Dolce
Elizabeth Earley
Connor Grannis
Laura Hart
Lauren Johnson
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Kelly Kelleher
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Garey Noritz
Lee Sanders
Madhurima Sarkar
Hannah Zaim

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