Development of an Adolescent-Reported Measure Assessing the Quality of Health Care Transition Preparation

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Health care transition (HCT) encompasses the process of preparing youth for the eventual move to adult-oriented care

- GOAL: provide high-quality and developmentally-appropriate health services in an *uninterrupted* manner
Health Care Transition (HCT)

• Lack of effective HCT may lead to:
  – Fragmentation of health care
  – Increased risk for adverse health outcomes
The Current State of U.S. Transitions?

Pediatric Care → Faith, Trust, and Pixie Dust → Adult Care
Preparation for HCT: A Quality Gap

- National Survey of Children with Special Health Care Needs (NS-CSHCN) – *Parent report*

![Graph showing shifts in prevalence of transition to adulthood discussions between 2005/06 and 2009/10 NS-CSHCN](www.childhealthdata.org)
Preparation for HCT: A Quality Gap

2007 Survey of Adult Transition and Health: Young Adult Report

- Discussed how health care needs might change: 55%
- Discussed health insurance coverage: 53%
- Discussed both health-related transition services: 34%
- Developed a transition plan at a school: 62%
- Reported receiving all 3 transition services: 24%
Preparation for HCT: Adolescent Perspective

• No survey has directly assessed adolescents’ report of the quality of transition preparation counseling
A New Measure

• The ADAPT (ADolescent Assessment of Preparation for Transition) survey is a youth-reported measure of the quality of health care transition preparation.
Overview of Measure Development

• Literature Review
• Expert interviews
• Focus groups
• Cognitive interviews
• National field test
• Psychometric analysis
• Composite development
Focus Groups

• 11 focus groups
  – Adolescents (16-18) and young adults (19-26) with chronic health conditions, as well as parents
  – Boston, Chicago, Los Angeles
  – Goal to inform domains and items for survey measure

• Major themes:
  – 16-18 year-olds: Ignorance and Fear
  – 19-26 year-olds: Suboptimal Preparation
  – Parents: Concern about Changing Roles

• The ADAPT survey was developed following the focus groups and refined via a series of cognitive interviews
The ADAPT Survey

• Mail survey designed for adolescents:
  – Age 16 or 17
  – With a chronic health condition(s)
  – Receiving health care services in a clinical program or enrolled in a health plan

• 26 questions total

• Three composite measures:
  – Counseling on Transition Self-Management (5 questions)
  – Counseling on Prescription Medication (3 questions)
  – Transfer Planning (4 questions)
Counseling on Transition Self-Management

This composite is produced by combining responses to five questions:

• **Q4:** In the last 12 months, did you talk with this provider without your parent or guardian in the room?

• **Q5:** In the last 12 months, did you and this provider talk about your being more in charge of your health?

• **Q6:** In the last 12 months, did you and this provider talk about your scheduling your own appointments with this provider instead of your parent or guardian?

• **Q7:** In the last 12 months, how often did you schedule your own appointments with this provider?

• **Q8:** In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?
Counseling on Prescription Medication

Respondents who answer “Yes” to both Questions 9 and 11 are included in the population for which this composite is calculated.

- **Q9**: In the last 12 months, did you take any prescription medicine?
- **Q11**: In the last 12 months, were you prescribed any medicine to take every day for at least a month?

This composite is produced by combining responses to three questions:

- **Q10**: In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?
- **Q12**: In the last 12 months, did you and this provider talk about remembering to take your medicines?
- **Q13**: In the last 12 months, did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian?
Transfer Planning

Respondents who answer “Yes” or “Don’t Know” to Question 14 are included in the population for which this composite is calculated.

- Q14: Does this provider treat mostly children and teens?

This composite is produced by combining responses to four questions:

- Q15: In the last 12 months, did you and this provider talk about whether you may need to change to a new provider who treats mostly adults?
- Q16: In the last 12 months, did this provider ask if you had any questions or concerns about changing to a new provider who treats mostly adults?
- Q13: In the last 12 months, did you and this provider talk about a specific plan for changing to a new provider who treats mostly adults?
- Q18: Did this provider give you this plan in writing?
Fielding the Survey

• Eligibility criteria
  • 16-17 years old
  • At least one chronic health condition
  • Clinical program: at least one visit during in the preceding 12 months
  • Health plan: current enrollment over the preceding 12 months with at least one administrative claim

• Sampling strategy
  • Clinical program: use Simple Random Selection (SRS) to draw from eligible patients
  • Health plan: apply an algorithm to claims data to determine eligibility, then use SRS to draw final sample
National Field Test

• Dates:
  – August 2013 – April 2014

• Location:
  – Massachusetts: Boston Children’s Hospital
    » 623 surveys mailed, 293 returned (47% response rate)
  – Pennsylvania: AmeriHealth Caritas Pennsylvania (AHCP)
    » 3,000 surveys mailed, 780 returned (28% response rate)
  – Texas: Texas Children’s Health Plan (TCHP)
    » 3,000 surveys mailed, 559 returned (21% response rate)
## Respondent Demographics

<table>
<thead>
<tr>
<th>Category</th>
<th>BCH</th>
<th>AHCP</th>
<th>TCHP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (% female)</td>
<td>54%</td>
<td>51%</td>
<td>56%</td>
</tr>
<tr>
<td>Age (% 16 years old)</td>
<td>42%</td>
<td>45%</td>
<td>40%</td>
</tr>
<tr>
<td>Insurance (% public)</td>
<td>29%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9th grade or less</td>
<td>7%</td>
<td>15%</td>
<td>10%</td>
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<tr>
<td>10th grade</td>
<td>39%</td>
<td>37%</td>
<td>33%</td>
</tr>
<tr>
<td>11th grade</td>
<td>47%</td>
<td>39%</td>
<td>38%</td>
</tr>
<tr>
<td>12th grade or more</td>
<td>7%</td>
<td>9%</td>
<td>19%</td>
</tr>
<tr>
<td>Race:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>83%</td>
<td>51%</td>
<td>16%</td>
</tr>
<tr>
<td>Black</td>
<td>5%</td>
<td>26%</td>
<td>19%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>7%</td>
<td>15%</td>
<td>58%</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>8%</td>
<td>8%</td>
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</tbody>
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ADAPT Composite Scores by Site

*Counseling on Transition Self Management (p=0.17)*
- BCH: 33%
- AHCP: 36%
- TCHP: 31%

*Counseling on Prescription Medication (p=0.03)*
- BCH: 62%
- AHCP: 53%
- TCHP: 59%

*Transfer Planning (p=0.33)*
- BCH: 8%
- AHCP: 6%
- TCHP: 5%

*p-value using Fisher’s exact test comparing scores across 3 sites*
Differences By Age or Gender?

- No differences in composite scores based on gender at any site
- 17 year olds had higher average scores in Transfer Planning in 2 sites
  - No differences in other composites
Reliability and Validity

• Internal consistency reliability (ordinal alpha)

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<tbody>
<tr>
<td>Counseling on Transition Self Management</td>
<td>.79</td>
<td>.70</td>
<td>.78</td>
</tr>
<tr>
<td>Counseling on Prescription Medication</td>
<td>.57</td>
<td>.78</td>
<td>.74</td>
</tr>
<tr>
<td>Transfer Planning</td>
<td>.99</td>
<td>.99</td>
<td>.99</td>
</tr>
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• Confirmatory factor analysis supported the hypothesis that the individual items within each of the first two domains are associated with one another
Limitations of the ADAPT Survey

• Cannot evaluate all important facets of HCT preparation
• Parents/guardians may be able to provide better information than adolescents about some aspects of HCT preparation
• Mail surveys may lead to bias / uncertainty on who answered
• Not appropriate to assess HCT preparation for adolescents who have cognitive or developmental delay.
Summary

• The ADAPT survey is a reliable, validated, patient-reported instrument to measure the quality of HCT preparation in adolescents with chronic disease.

• Results from the field tests indicate that preparation for HCT is suboptimal.
  – Overall, the quality of HCT preparation is highest for prescription medication counseling.
  – Low levels of counseling on self-management and transfer planning are evident among adolescents in varied settings.
Future Directions

- Expanded use of the ADAPT survey will allow for comparisons based on other clinical and sociodemographic factors.
- The ADAPT survey will enable health care delivery systems to assess the quality of provision of HCT preparation and provide targets for improvement in patient counseling related to transition.
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