

Planning for Transition from Pediatric to Adult Health Care for Youth with Mobility Limitation

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Disclosure

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No relationships to disclose

Learning Objectives

- Discuss the health care transition issues facing youth with mobility limitation.
- Explain associations between mobility limitation and measures of transition planning.
- Describe components of medical home that are associated with transition planning.

Background

- Health care transition increasingly significant issue (Kennedy, 2008)
 - More young people with chronic illness and disability moving to adulthood
 - Health care delivery more complex
- Many young adults with special healthcare needs know little about health care transition (Lotstein, 2008; McManus et al., 2008)
 - more than one-half feel they are not prepared when they transfer to adult care

Background (cont.)

- In the 2007 National Survey of Children with Special Health Care Needs, 28% of youth with mobility limitation ages 0-17 years (n=5,162) had a medical home, compared with 47% of youth with all other special health care needs (n=31,708) (Bell et al., in prep).
- No studies: Is medical home is positively associated with health care transition planning for youth with mobility limitation?

Study Objectives

1. Test associations between mobility limitation and transition planning, including receipt of health care advice.
2. Examine whether specific components of medical home are associated with transition planning.

Data Source and Sample

- National Survey of Children with Special Health Care Needs, 2005–2006 (parent-report)
- Youth ages 12–17 years
- Receiving health care from pediatric provider only
- n=18,179

Study Variables: Mobility Limitation

- Defined as restrictions in function/activity rather than by diagnostic category (WHO ICF, 2001):

“Compared to other children of the same age, does the child experience difficulty with coordination or moving around, such as walking or running?” (NS-CSHCN)

- Includes congenital conditions (e.g. spina bifida), disease-related impairments (e.g. juvenile arthritis) and other causes (e.g. cerebral palsy, spinal cord injury)

Study Variables: Medical Home

- Binary (no, yes) based on algorithm developed by the Child and Adolescent Health Measurement Initiative (CAHMI)

- Five components:
 1. Personal doctor or nurse
 2. Usual source of care
 3. Accessible
 4. Family-centered
 5. Coordinated

Study Outcomes: Transition Planning and Health Care Transition Advice

- Transition Planning: Meets criteria for receiving services necessary to making transition to all aspects of adult life, including health care, work, and independence

- Health Care Transition Advice:
 1. Provider discussed shift to an adult provider, if necessary;
 2. Provider discussed future health care needs, if necessary;
 3. Provider discussed future health insurance care needs, if necessary;
 4. Provider encouraged youth to engage in age-appropriate self care (ages 13-17 only)

Covariates

- All analytic models controlled for variables expected to confound relations between mobility limitation and transition planning
- 1. Sex, Age, Race/ethnicity
- 2. Census region
- 3. Family structure
- 4. Family income (% federal poverty line)
- 5. Health insurance status
- 6. Highest education anyone in household
- 7. Severity of the youth's condition
- 8. Youth prescription drugs
- 9. School absences prior year

Statistical Analysis

- Cross-sectional analysis of associations between mobility limitation, medical home, and transition planning
- Logistic regression, controlling for covariates
 - With and without medical home
 - Stratified by mobility limitation
 - Survey-weighted estimates
- Stata (College Station, TX) Version 10.1

Characteristics of Youth Ages 12-17 Years with Special Health Care Needs by Mobility Limitation
NS-CSHCN, 2005-2006 (n=18,179)

| | Mobility Limitation^a (n=2,545) | Other Special Health Care Needs (n=15,634) | |
|---|---|---|----------|
| | % | % | p |
| Age (years) | | | 0.76 |
| 12-14 | 50 | 49 | |
| 15-17 | 49 | 50 | |
| Sex | | | |
| Female | 45 | 42 | 0.25 |
| Race/Ethnicity | | | 0.02 |
| White non-Hispanic | 66 | 69 | |
| Black non-Hispanic | 17 | 15 | |
| Hispanic | 10 | 10 | |
| Other non-Hispanic | 7 | 6 | |
| Insurance | | | <0.01 |
| Private Only | 48 | 67 | |
| Public Only | 26 | 14 | |
| Other | 21 | 15 | |
| None | 5 | 4 | |
| Family Income level (%FPL) | | | <0.01 |
| <200% FPL | 48 | 33 | |
| 200 - <399 % FPL | 25 | 27 | |
| >= 400% FPL | 27 | 40 | |
| School Absences (days in prior year) | | | <0.01 |
| 11 or more | 29 | 14 | |
| Severity of Youth's Condition | | | <0.01 |
| Mild | 19 | 62 | |
| Moderate | 52 | 32 | |
| Severe | 29 | 6 | |

^a Mobility limitations defined by parent report of functional limitation

Results: Receipt of Pediatric Care Only

- Youth with mobility limitation (65%) were more likely than those with other special health care needs (59%) to report that their medical provider treated children only:

Adjusted Odds Ratio = 1.28; 95% CI: [1.07, 1.53]

Transition Planning and Advice in Mobility Limitation and All Other CSHCN

| | Mobility Limitation % | Other CSHCN % | Adj OR [95% CI] | |
|---------------------------|-----------------------------|---------------------|-------------------|----|
| Age-Appropriate Self Care | 55 | 83 | 0.35 [0.27, 0.46] | ** |
| Future Health Care Needs | 50 | 61 | 0.65 [0.50, 0.86] | ** |
| Shift to Adult Provider | 32 | 44 | 0.61 [0.44, 0.85] | ** |
| Future Health Insurance | 28 | 33 | 0.97 [0.70, 1.34] | NS |
| All Components | 26 | 36 | 0.65 [0.50, 0.86] | ** |

** p < .01; NS = Not significant

Youth with Mobility Limitation: Medical Home and Transition Planning

| | | |
|---|------------------------|----|
| MODEL 1: Has Medical Home | Adj OR [95% CI] | |
| | 3.48 [2.34, 5.16] | ** |
| MODEL 2: Medical Home Components | Adj OR [95% CI] | |
| Family-Centered Care | 2.09 [1.45, 3.01] | ** |
| Personal Doctor or Nurse | 1.78 [0.63, 5.04] | NS |
| Care Coordination | 1.72 [1.16, 2.58] | ** |
| No Referral Problems | 0.89 [0.67, 1.18] | NS |
| Usual Source of Care | 0.75 [0.35, 1.63] | NS |

** p < .01; NS = Not significant

Youth with Mobility Limitation: Medical Home and Receipt of Transition Planning Advice

| <i>Doctor discussed:</i> | Medical Home | |
|-------------------------------|--------------|-----|
| | Yes | No |
| Future health care needs | 76% | 42% |
| Shift to an adult provider | 55% | 27% |
| Future health insurance needs | 48% | 18% |

Summary

- Youth with mobility limitation in pediatric care are less likely to receive transition planning advice than are other CSHCN.
- Care in a medical home is associated with receipt of transition planning advice in this population.

Summary (cont.)

- For youth with mobility limitation, family-centered and coordinated care is important for planning the transition from pediatric to adult health care.
- Having a personal doctor or nurse or a usual source of care is not sufficient by itself for transition planning.

PDN

Child has one person whom parent considers to be child's personal doctor or nurse

Accessible care

Can get advice by telephone

Gets appointment as soon as wants for routine care

Gets appointment as soon as wants for illness/injury

Waits <15 min during appointments

Family-centered, compassionate care

PDN who knows child

PDN talks with parent about how child is feeling, growing, and behaving

PDN understands how health condition affects child's day-to-day life

PDN understands how health condition affects family's day-to-day life

Doctors who communicate well: child's doctors and other health care providers

Listen carefully to parent

Explain things understandably to parent

Respectful of parent

Explain things understandably to child

Spend enough time with child

Getting needed information: child's doctors and other health care providers

Make it easy to discuss questions or concerns

Give specific information that needed

Answer parents questions

Shared decision making: child's doctors and other health care providers

Offer choices about child's care

Discuss pros and cons of each care option

Ask which care option parent prefers

Involves parent as much as s/he wants

Comprehensive care

Getting needed care

- Finding a PDN with little or no problem

- Getting a referral to specialist child needs to see

- Getting care that parent or doctor believes necessary

- Delays in care as a result of waiting for approval from child's health plan

Getting specialized services

- Getting special medical equipment needed by child

- Getting specialized therapy for child

- Getting treatment/counseling for child's developmental, behavioral, or emotional problem

Getting prescription medicines

- Getting prescribed or refill prescription medication for child

Coordinated care

Coordination of care

- Family gets help coordinating child's care among multiple doctors/services

Communication with school/child care

- Doctor communicates with school or child care about child's health needs