Transition in Practice:

A KAP survey of medical genetics health professionals in the Heartland Regional Genetics and Newborn Screening Collaborative

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Disclosures

- None
Defining Healthcare Transition

“Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult oriented health care system”


Defining Healthcare Transition

- **1996**: AAP Committee on Children with Disabilities & Committee on Adolescents
  - explained why a coordinated process of transition is important
  - highlighted need for cooperation between multiple care providers
- **2002**: outlined critical steps to ensure a successful transition
- **2011**: Reaffirmed goals of transition process
  - Very few advances over past 10 years
Heartland Regional Genetics and Newborn Screening Collaborative

Aims of the Heartland Transition Project:

(1) Describe the role of the medical genetics team in health care transition of youth with genetic and chromosomal conditions.

(2) Describe effective health care transition strategies applicable for use by the medical genetics team.

Three strategies used to accomplish these aims.

(1) Learning Collaborative (LC) with medical genetics clinics in Denver and the Heartland region Oklahoma City and Wichita).

(2) Online, anonymous survey of pediatric genetics service providers of their knowledge, attitudes, and practice behaviors regarding health care transition.

(3) Qualitative data collection effort
KAP Survey Purpose

- Gather baseline information
  - Develop relevant education initiatives
  - Design successful standards of practice
- Future assessment
  - Changes in practice
  - Evolution of topic

Knowledge
Attitudes
Practices
Methods: Survey Design

- **Demographics (Ten questions)**
  - Gender, age, region, professional role, years of experience, professional setting, patients’ age, and percent of patients seen for management

- **Knowledge (Six questions)**
  - Definitions, familiarity, experience, modes of education

- **Attitudes (Seven questions)**
  - Factors of transition, timing, responsibilities

- **Practices (Seven questions)**
  - Materials, protocols, actions, resources, barriers

Methods: Population

- **Potential participants were recruited from the Heartland membership**

- **Target population**
  - medical geneticists
  - genetic nurses
  - genetic nurse practitioners
  - genetic counselors
  - other members of the genetics healthcare team

- **105 genetics providers from the Heartland region were invited to participate, 55 providers responded (52% response rate)**
Methods: Data Analysis

- SurveyMonkey® data exported to Excel and SPSS
- Opinions rated on Likert scales and analyzed by comparing the mean ratings
- Group responses compared using Chi-square analysis and Fisher's exact test.
- Responses compared across professional role and level of experience
- All statistical tests assessed at an alpha level of 0.05.

Results: Demographics
Results: Demographics

Primary role:
- Medical Geneticist (n=16)
- Registered Nurse (n=3)
- Advanced Nurse Practitioner (n=6)
- Genetic Counselor (n=29)
- Physician’s Assistant (n=1)
- Other (n=1)

Please estimate what percent of your patients are ages:

- Birth-5y
- 6y-11y
- 12y-17y
- 18y+
Results: Knowledge

How would you rate your knowledge of healthcare transition?

- Very minimal (n=7): 14.9%
- Minimal (n=13): 27.7%
- Moderate (n=27): 57.4%
- Extensive (n=0): 0.0%
- Very extensive (n=0): 0.0%
Results: Knowledge

“Please define/explain what health care transition means to you. . .”

- Process (12.5%, n=6)
- Transfer or move (54.4%, n=26)
- Age or maturity dependent (93.8%, n=45)
- All three elements (73%, n=35)
Results: Attitudes
Results: Attitudes

In your opinion, how important is each of the elements listed below to the process of transition as a whole?
**Results: Attitudes**

**“At what age should transition begin?”**
- Range: Birth → 21y
- Most answered 12y-18y
- Notable comments
  - Depends on “level of functioning”
  - Transition discussion vs. physical transition

**Results: Attitudes**

- Who should be responsible for ensuring a successful healthcare transition process?

<table>
<thead>
<tr>
<th>Option</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multi-person or team approach</td>
<td>29</td>
<td>72.5%</td>
</tr>
<tr>
<td>Primary are physician as central player</td>
<td>17</td>
<td>42.5%</td>
</tr>
<tr>
<td>Patient and/or family as central player</td>
<td>18</td>
<td>45.0%</td>
</tr>
<tr>
<td>Specifically mentioned genetics</td>
<td>7</td>
<td>17.5%</td>
</tr>
<tr>
<td>No mention of healthcare providers</td>
<td>3</td>
<td>7.5%</td>
</tr>
</tbody>
</table>

(n=40)
Results: Attitudes

■ What issues should be addressed by the MG team?

■ Transition issues that SHOULD BE addressed by the Medical Genetics team
■ Transition issues CURRENTLY being addressed by the Medical Genetics team

> Results: Attitudes

“Please rate your opinion regarding the following statements . . .”

■ Most agreed upon
  □ “Transition applies to genetics patients”

■ Least agreed upon
  □ “Transition resources should be standard regardless of age”
  □ “It is the role of the medical genetics clinic to coordinate patients’ care”
Results: Practices

- Utilization of resources
  - support groups ↑
  - fitness/activity center ↓

- Frequency of transition actions
  - involve the family in transition planning ↑
  - schedule a visit focused on transition ↓
Discussion

- Moderate understanding of transition concepts
- Low representation of complexity of transition
- Attitudes vs. practices
- Low utilization of transition-specific tools
- Age/period for transition
- Physical shift vs. psychological shift
Discussion: Limitations

- Survey distribution
- Possible ascertainment bias
- Not possible to know how respondents compare to the entire population
- Difficulty with software compatibility
- Self-response questions: subject to variability in participants’ self-awareness
- Comparison between groups often failed to fit criteria for statistical analysis

Conclusions

- Concept of “healthcare transition” → accepted
- Less evidence of deeper understanding and implementation
- Low use of transition tools and discussion of transition in the medical genetics clinic
- Providers would benefit from
  - education initiatives
  - suggested transition protocols
  - introduction of transition tools
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References


Thank you to everyone who participated!

Excuse me... on a scale from 1 to 5, with 1 being "always" and 5 being "never," how often do you answer random questions from people on the street?