

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”

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health 14*(7), 570-576. doi:10.1016/1054-139X(93)90143-D

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.



Heartland Regional Genetics and Newborn Screening Collaborative

- 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

KAP Survey Purpose

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

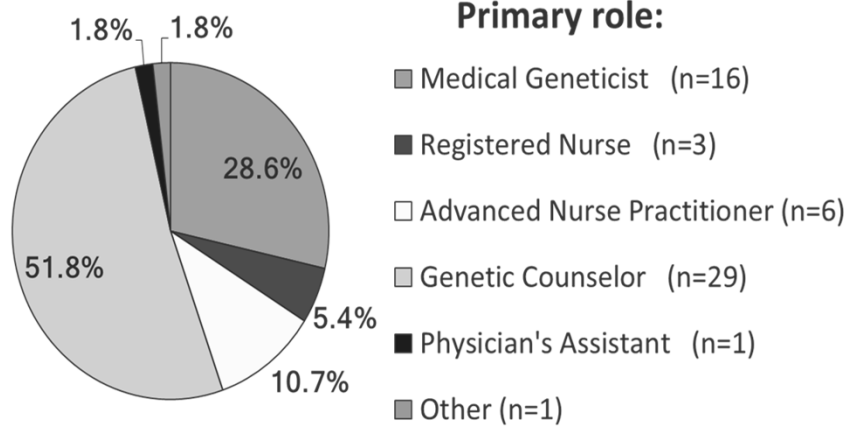
- **Potential participants were recruited from the Heartland membership**
- **Target population**
 - medical geneticists
 - genetic nurses
 - genetic nurse practitioners
 - genetic counselors
 - other members of the genetics healthcare team
- **105 genetics providers from the Heartland region were invited to participate, 55 providers responded (52% response rate)**

Methods: Data Analysis

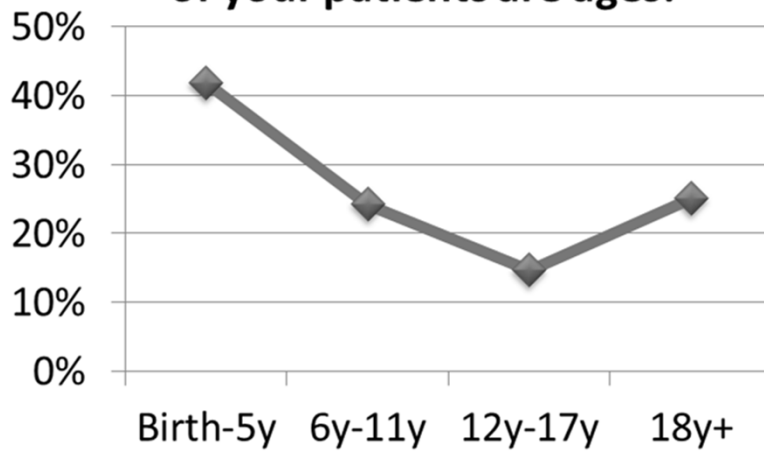
- SurveyMonkey® data exported to Excel and SPSS
- Opinions rated on Likert scales and analyzed by comparing the mean ratings
- Group responses compared using Chi-square analysis and Fisher's exact test.
- Responses compared across professional role and level of experience
- All statistical tests assessed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

Results: Demographics

Results: Demographics



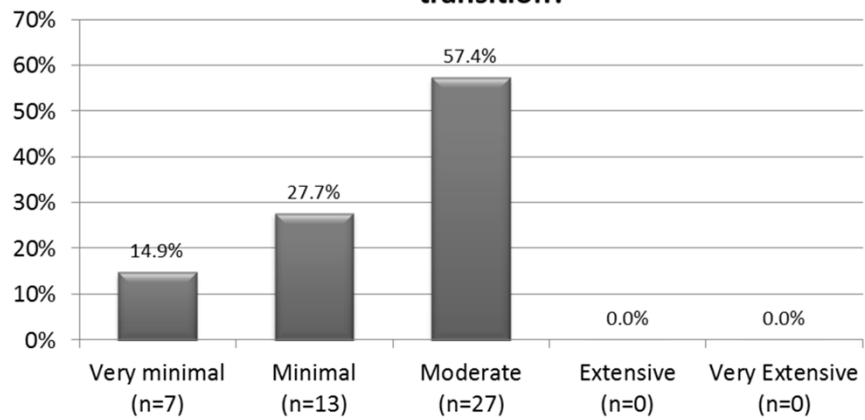
Please estimate what percent of your patients are ages:



Results: Knowledge

Results: Knowledge

How would you rate your knowledge of healthcare transition?

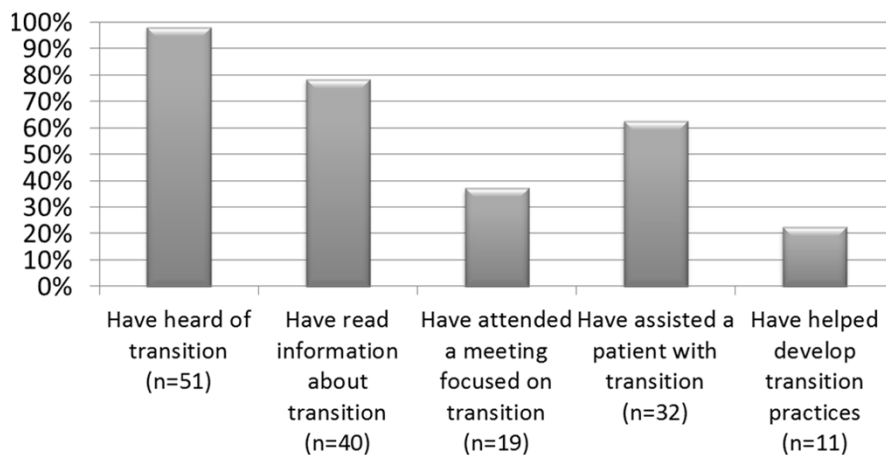


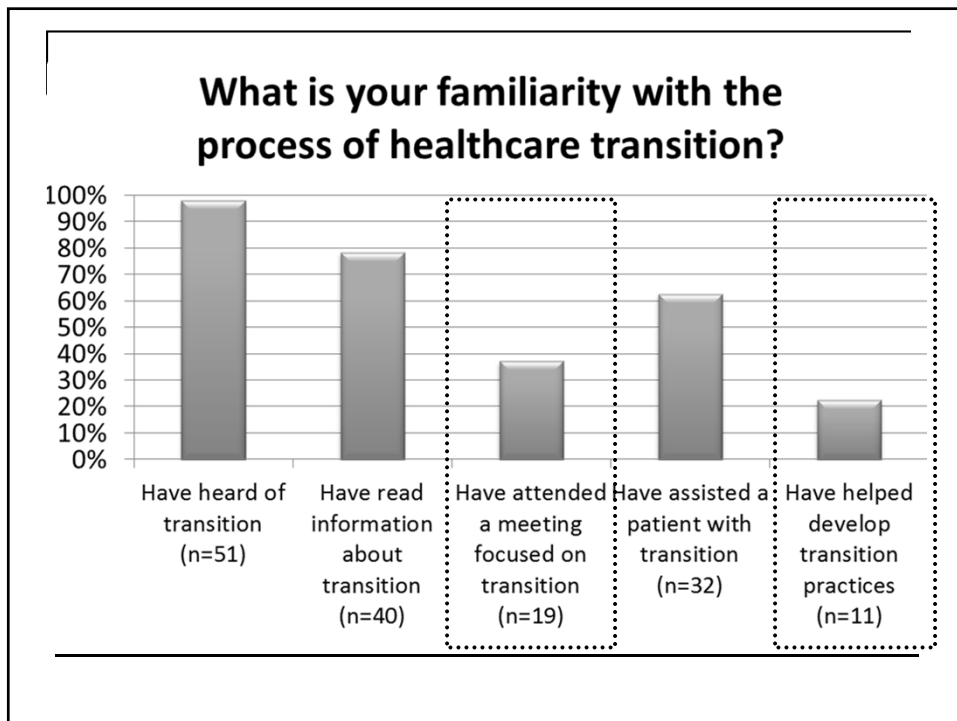
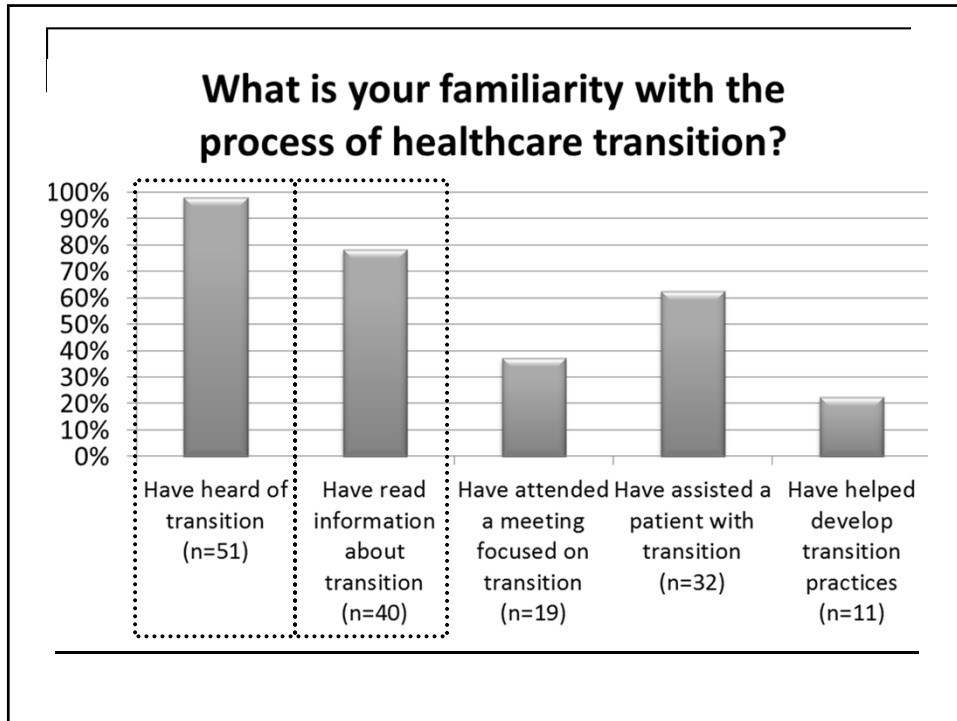
Results: Knowledge

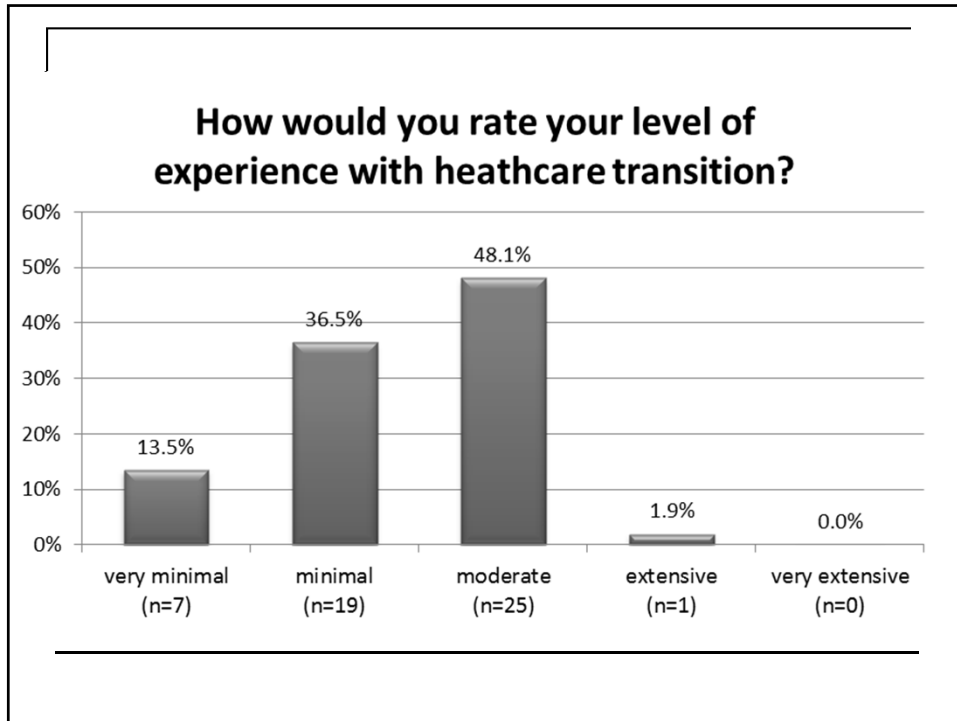
“Please define/explain what health care transition means to you. . .”

- 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)

What is your familiarity with the process of healthcare transition?



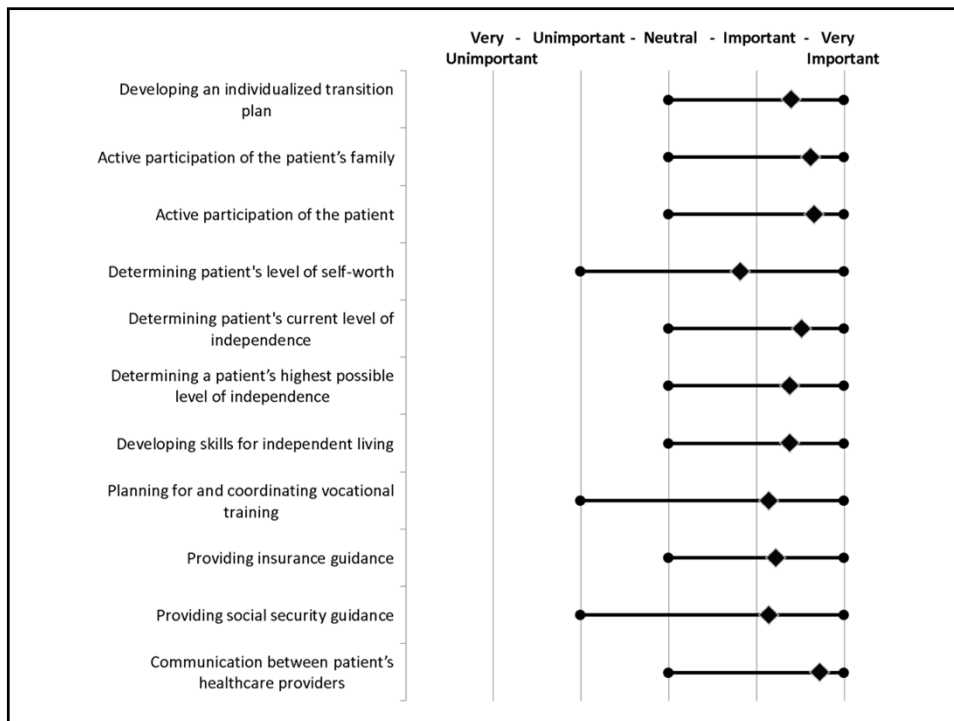




Results: Attitudes

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

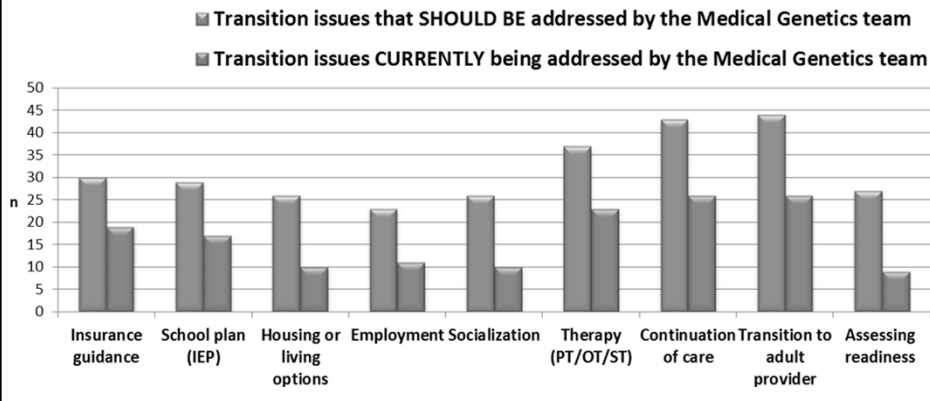
- Who should be responsible for ensuring a successful healthcare transition process?

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

(n=40)

Results: Attitudes

- What issues should be addressed by the MG 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

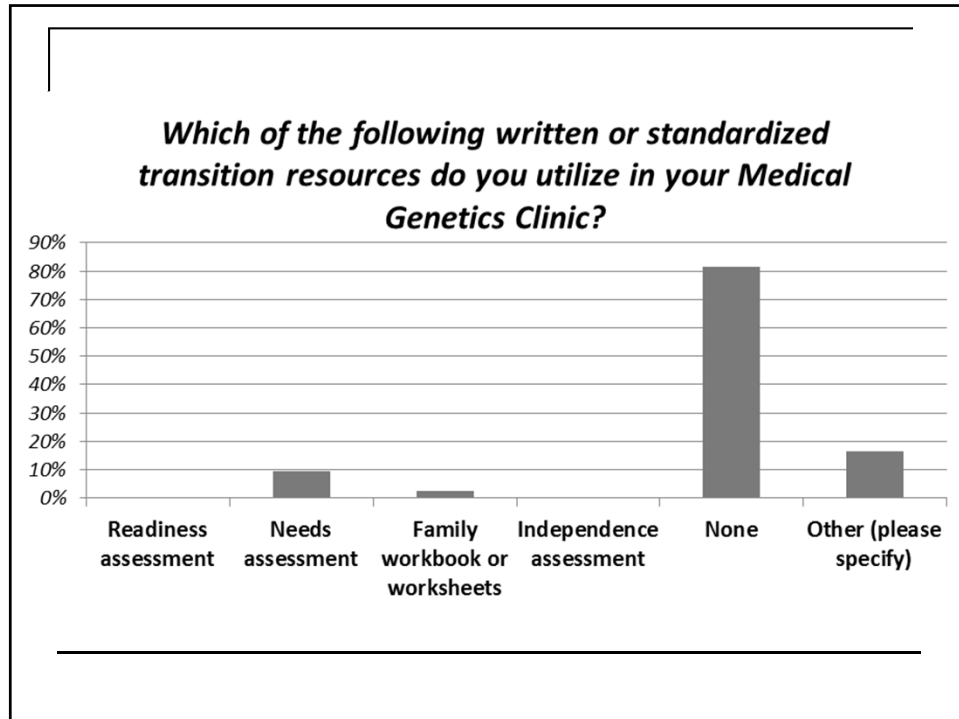
Results: Practices

■ 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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