Transitioning Adolescents and Young Adults with Childhood Onset Conditions Into the Adult Milieu of Health Care and the World Beyond:

Patient Video Interviews

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I have no financial relationships to disclose.
Transition of care from pediatric to adult health care providers is an especially anxiety-provoking time for those with special needs, their families, and health care providers. No clear guidelines for transition process exist. Process is complicated by physical and cognitive impairments. Transition process is gradual, involving many different providers and family members. Young adult must learn to self-advocate and assume responsibility for tasks, if possible. Suboptimal transition has been shown to generate unfavorable outcomes on quality of life, access to care, disease outcomes, education, and employment. Increased frequency of missed appointments, hospitalizations, mortality.

Video Interviews
Introduction

- Video interviews with 10 Young Adults with disabilities and 2 parents
- In varying stages of transition process
- Ages 21-29
- 2 sets of twins
- Different diagnoses
- Cognitive abilities
- College and non-college
- Mobility levels
- Employment and volunteering
**Video Themes: Barriers**

**Adult Providers**
- Familiarizing adult providers with CP
  - limited adult providers willing to accept patients\(^1\)
  - concern that adult healthcare provider will not provide same level of care\(^1\)
- Botox under anesthesia
- Being okay with managing symptoms rather than fixing or improving them

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Video Themes: Barriers

- Appropriate age to discuss transition
  - AAFP and AAP recommend HCT being around age 12\(^1\)
  - Introductory session and assessment of readiness\(^2\)
  - Varying developmental, cognitive, cultural, literacy, and linguistic needs\(^2\)

- Multidisciplinary approach
  - Coordination of pediatric and adult providers
  - Ideal health care setting for adults with CP identified as a comprehensive, multidisciplinary, adult-focused clinic in an adult hospital with adult providers\(^3\)

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Video Themes: Barriers

- Parental involvement
  - Organization skills
  - Consent process
  - Self advocacy and decision making
  - Parent/caregiver needs/engagement in transition process
  - Parental resistance to transition

- Comorbid mental health issues
  - Difficulty with social interactions (telephone)
  - Anxiety (especially without parents)

Video Themes: Post High School

- College
  - Adjusting socially
  - Transportation and Mobility
  - Academic Accommodations

- Non-college options
  - 18-22 and adult programs
  - Job training/Vocational Rehab
    - Those in work-based programs more likely to be employed as adults
  - Difficulty obtaining OT/PT services after high school

Video Themes: Post High School

- Having a job
  - Social interactions at work
  - Job satisfaction
  - SSI
    - Difficulty understanding SSI and determining how much patient is able to earn and still retain benefits

- Interacting with co-workers
  - Worried about not being taken seriously
  - Not wanting to be seen as “inspirational”

Video Interviews
References


13. [https://www.med.unc.edu/transition](https://www.med.unc.edu/transition)