

Young Adults with CP: What They Say, What Researchers Say and Why we Should Listen

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**Surprise! We're Still
Here**



Purpose

- The purpose of this presentation is to briefly overview:
 - challenges related to CP in young adulthood and beyond through case vignettes
 - literature on pain as one of the most commonly cited conditions associated with CP and aging
- With a focus on transition-age youth (18-22) as a critical time to make sure health care needs are met and maintained with a “disability friendly” multifaceted approach

Who Are Adults with CP?

- Likely have unmet health care needs. Some of these may be related to CP
- They are likely unemployed/underemployed
- Likely receiving any of the following publicly funded supports: SSDI, Medicaid/Medicare, vocational rehab supports
- Likely single, living alone or with family
- Likely relying on a range of formal and informal supports for ADLs/IADLs

Background— Young Adults

- Transition age (18-22) young adults commonly face additional challenges including:
 - Transition to adult health care system
 - Changes in health insurance
 - Decisions about college/employment
 - Changing role of parents
 - In addition to coping with CP

Background–Young Adults

- Some studies have a wide age range, however most study populations comprised of mostly young adults (<35 yo)
- Secondary conditions related to CP may first become apparent during late teens/ young adulthood

Kevin

- 29 yo male; mixed CP
- Powered mobility user, limited independent ambulation
- Part-time freelance employee. Relies on Medicaid buy-in for health care and PCA benefits
- Reports very limited pain. Mainly concerned with obtaining appropriate DME and repairs when needed
- “I spent my childhood in doctor’s offices. I just got burned out. I’ll see my neurologist if I need paperwork filled out, but that’s it.”

Lisa

- 23 yo female; spastic diplegia
- Ambulates with Kaye walker, no w/c
- LBP and increased fatigue with walking
- Seeking employment but concerned about the demands of full-time employment on her body
- Has not seen a CP specialist in over 6 years
- Engages in LE and UE strength training 3x/week with help of a trainer
- “I am scared about my future. CP is one thing... having pain as well is almost too much.”

Kristen

- 33 yo female, R hemiplegia
- Ambulates independently
- 2 daughters
- Fractured R ankle during 2nd pregnancy
- Works full time in an academic setting
- Receives Botox and short course PT as needed
- “I feel like I need to ‘police’ my own health care. There’s just not enough hours for me to work, raise my kids, and attend multiple appointments per week. I can’t tell if the PT even works”

Pain as a Secondary Condition

- Engel et al. (2003)
 - n=100
 - 67% reported pain in ≥ 1 site (back, hip, LE)
 - Of those reporting pain, 50% felt it was a minor problem, while 3% felt it was their most significant problem
 - 33% dissatisfied with pain management
 - 13% were very or completely dissatisfied with pain management

Pain as a Secondary Condition

- Turk et al. (1997)
 - Survey of community-residing women in the community (n=63)
 - 84% reported pain in at least one area (head, back and arm most common)
 - This population reported positive health behaviors (low prev. of ETOH use, smoking, 83% reported exercise at least once a week)
 - Women who did not walk or who used a w/c were less likely to exercise

Transitioning into Adult-Centered Care

- Binks et al. (2007) identified barriers to, and facilitators for transition
 - Health care utilization decreases after age 18 for persons with CP and SB.
 - Roughly 1/3 of adults age 25-36 report having any rehab specialist visit in past year.

Barriers to Transition

- **Pediatric providers:** reluctance to “let go” of patients, distrust of adult-centered services
- **Youth:** little incentive to transition, feeling that “everything’s been done,” reluctance to leave safety net of pediatric providers, reluctance to take on the responsibility of care
- **Parents:** inability or reluctance relinquish control or to become less engaged with child’s care
- **Adult providers:** limited training/knowledge, lack of resources to treat complex patients

Facilitators for Transition– Process vs. Event

- **Flexible timing:** dependent on health, familial and environmental factors
- **Preparation:** long prep period, perhaps begin talking about transition at dx. Continuous support and for family and patient
- **Coordination:** tx plan, service plan, up-to-date medical records, care coordination
- **Transitional visits:** Attend adult clinic with “evaluation period”
- **Interested, engaged adult-centered providers:** address condition and social factors, willing to address adult issues (drug use, sexual health, mental health)

Aspects of a Medical Home for Adults with CP

- Location, location, location!
- Multi-disciplinary approach
 - PMR
 - Orthopedics
 - PT/OT/ST
 - DME/OP
 - Mental Health
 - Social Supports
 - Care Coordination/Case Management/Transition Services
 - Complementary and Alternative Therapies
 - Health Promotion Services
 - Peer Support

Aspects of a Medical Home for Adults with CP

- Information related to:
 - “Disability friendly” primary care
 - OB/Gyn
 - Other specialties
- Potential Partners
 - Independent Living Centers
 - Other non-profits
 - State Agencies
 - Academic Partners

Questions and Comments?