Purpose

Highlight considerations for developmentally-appropriate rehabilitation, specifically focusing on needs and perspectives of adolescents and young adults (AYAs) with acquired spinal cord injuries (SCIs) to inform approaches to care.

Background

Developmental Considerations in Adolescence/Young Adulthood:

- Onset of puberty and continued maturation of musculoskeletal systems2-3
- Executive functions for self-organization and decision-making are still maturing4 – decisions are largely based on short-term concerns/interests5 Risk-taking
- Increased interest in peer relationships; less emphasis on family6
- Seeking independence7 Conflict between autonomy and reliance on family
- Exploring future possibilities; focus on pursuit of academic, career interests and identity-formation8
- Many health risks, including elevated rates of psychological stress and suicidal ideations, participation in risky behaviors, and onset of chronic conditions that indicate lifelong use of health care9

AYAs with Spinal Cord Injuries:

- Comprise nearly 50% of annual incidence of SCI in the US10
- Physical and psychosocial consequences of SCI impact quality of life10-12
- Participation and autonomy are currently challenged by changed abilities, social roles, and environments13-14

Methods

Multi-phase, narrative16 and phenomenological16 design:

- Probes focused on everyday life and experiences relating to participation in rehabilitation and transitions to community life following acquired SCI
- Interviews were audio recorded and transcribed verbatim for coding in NVivo11.
- Data analyzed categorically, thematically, and narratively, within- and across-cases, to evaluate interrelations of experiences and developmental trajectories.

Results

AYA characteristics from self-report at time of enrollment:

- Time Since Injury (1-53m)
- Level of Injury
- Medical
- Cervical
- Thoracic
- Location
- Unspecified

AYA1: AYA2:

Usage of database revealed:

- Complex negotiations in day-to-day life were required for AYAs to pursue desired, age-appropriate experiences while also participating in rehabilitation and/or maintaining health. This included management of compounded risks.
- Resources (cognitive, social, environmental) and experience significantly influenced knowledge of possibilities and pursuit of desired futures.
- Day-to-day experiences, from mundane to extraordinary, influenced reconstruction of "self" or identity after SCI. This included participation in changed bodies, shifting social communities, and coordination with caregivers.
- Drastic shifts in physical abilities and social support limited feelings of autonomy.
- Tensions between development/interests/priorities and models of healthcare.

Data excerpts revealed themes, situated in lived experiences, across cases:

AYA1:

“Risky” Behaviors (sex, alcohol, drugs)

Autonomy

Identity-Formation

Social Worlds

Future Possibilities

References available by request: chaywood@usc.edu
Select References