Self Management and Health Care Transition: Trials, Tribulations and Triumphs

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• Does not intend to discuss commercial products or services.

• Does not intend to discuss non-FDA approved uses of products/providers of services.
Self Management and Health Care Transition

“…is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination…”

(AAP, AAFP, ACP-ASIM, 2002)
Self Management and Health Care Transition

Health Care Transition (HCT) refers to the comprehensive services based upon an interdisciplinary framework of care that addresses the biopsychosocial needs of early adolescents (11-15 years of age), late adolescents (16-18 years of age), and emerging adults (18-25 years of age). This framework of services is utilized throughout the lifespan and intensifies in early adolescence to ensure adolescents and emerging adults learn the self-management knowledge and skills necessary to manage their daily treatment needs as independently as possible and become a literate health consumer. Comprehensive services include coordination of care that involves referrals to the service systems of education and training, employment, community living, rehabilitation and advocacy. (Society of Pediatric Nurses, 2017)
Self Management and Health Care Transition

Transfer of Care:

Transfer of care refers to the dual process of locating and arranging primary, specialty and interdisciplinary health care providers who provide care to adolescents as their eligibility for services provided by pediatric providers ends.

(Society of Pediatric Nurses, 2017)
2002 Consensus Report
American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-
American Society of Internal Medicine

• Identified HCP responsible for transition planning
• Identification of core knowledge and skills needed for HCT
• Portable and accessible medical summary
• Written HCT plan by age 14 reviewed and updated annually
• Primary and preventive care guidelines apply (i.e. Bright Futures)
• Access to affordable and uninterrupted health insurance
“The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth including those who have special health care needs and those who do not.” (Cooley et al., p. 182, 2011)
What are the Best Practices?

• AAP, (1996)
• AAP, AAFP, ACP, ASIM, (2002, 2011)
• SAM (Rosen et al., 2003; Blum et al. 1993)
• HRTW, Maternal Child Health Bureau, with Special Health Care Needs
• Got Transition? (2014, 2015, 2016)
• Society of Pediatric Nurses (2017)
Self Management: What We Learned

• Started our experience in learning more about self management in 1997

• Focus groups conveyed their lack of preparation for life
  • Now that I’ve graduated from high school, what am I suppose to do
  • I wasn’t expected to live until now, so what do I do?

• Led us to develop a comprehensive tool to assess range of health-related needs for adulthood in 1998
  • California Healthy and Ready to Work Health Care Transition Assessment
Have needed environmental modifications/accommodations:

1. Do you have the necessary electrical supports and equipment?

2. Do you storage space for your supplies and equipment?

3. Does your home have wheelchair ramps and other housing modifications (doors, tubs with hand rails)?

4. Are you able to safely recycle/dispose of supplies?
What to do in an emergency

1. Do you have a phone to use in case of an emergency?

2. Do you have the phone numbers of family and friends to call in emergencies?

3. Do you have the phone number of the paramedics?

4. Do you know where the closest hospital emergency department is?

5. Have you contacted the fire department of your special needs in case you have to evacuate?

6. Have you contacted the gas/electric companies if you have more than usual service needs?
Self Management

- Is a process and it is not linear.
- Involves many moving parts.
- Requires visuals and technology.
- Assumptions are not warranted!
- Constant review and re-instruction is needed
- Saving face is a reckoning force.
- Needs for learning change.
- If it could only be so simple!
Self Management

• Determination of baseline is essential and ongoing.
• Scaffolding of skills is individualized
• One size does not fit all
• Self management needs to be conceptualized in terms of hierarchy of skills
  • Immediate; daily management needs
  • Peripheral linked to daily needs (setting, circumstances, logistics)
  • Linkages to the family/social supports
  • Linkages to community
• Patterns of self management are not predictable
Self Management: What We Learned and are Learning

- How and when to disclose information about their lived SB experience
- Medications
  - Reasons
  - Side Effects
  - Effectiveness
- Learn to use a Phone Tree
- Access websites pertaining to SB
- Use iPhone apps
- Fully informed choices
Self Management: What We Learned and are Learning

- Providers who are disability-sensitive
- Offices with disability-related durable medical equipment
- Supplies specifications
- Informed about high risk activities
- Learn to file complaints with Civil Rights offices; customer services
- Understand benefits associated with insurance plans and other programs
- Use of visuals pertaining to SB and surgical treatments
- Making “cold calls”
Self Management: What We Learned and are Learning

• Dealing with social situations
  • Sleep overs
  • Camps
  • School trips
  • Casual outings with friends
  • After school events

• School-related issues
  • Disclosure
  • Wear of braces/use of assistive devices
  • Clothing
  • Changing for PE
  • PE performance expectations
  • Provision of health-related accommodations
  • 1 to 1 school aide
  • Privacy issues
HCTRC Model and Self Management

• Environment
  • Health Related Accommodations in Educational/Employment Settings
  • Issues pertaining to Disclosure
  • Accessible Recreational Areas
  • Community Inclusion
  • Available transportation

• Health Care System Domain
  • Transfer of Care
  • Enrollment in Health Insurance Plan
  • Supplies and Durable Medical Equipment
HCTRC Model and Self Management

• Family/Social Support Domain
  • Health Related Accommodations
  • Issues pertaining to Disclosure
  • Dependency pertaining Activities of Daily Living

• Individual
  • Bowel and Bladder Management
  • Skin Care
  • Managing Minor Illnesses
HCT instruments

• STARx Questionnaire (Ferris et al., 2015)

• The Transition Readiness Assessment Questionnaire (TRAQ) (Wood et al., 2015)

• UNC TRxANSITION Scale (Ferris et al. 2012)

• Measuring Transition Readiness: A Correlational Study of Perceptions of Parent and Adolescents and Young Adults with Sickle Cell Disease (Speller-Brown, et al. 2015)
HCT instruments

Healthy and Ready to Work HCT Assessment (Betz et al., 2005)

Assessing readiness for transition from paediatric to adult health care: Revision and psychometric evaluation of the ‘Am I ON TRAC for Adult Care’ questionnaire (Moynihan et al., 2015)
Self Management: Critical Life Span Competencies

- ↑ Independence
- ↑ Productivity
- ↑ Self-determination
- ↑ Self-efficacy
- ↑ Well-being
- ↑ Self-reliance
- ↑ Quality of Life

Betz et al., 2015; Betz et al., 2013; Bloom et al., 2012; Campbell et al., 2016; Coyne et al. 2017; Crowley et al. 2011; Fair et al., 2015; Findley et al., 2015; Fredericks et al., 2011; Maturo et al., 2015; Prior et al., 2014; Scalda et al., 2017; Schultz et al., 2017; Speller-Brown et al., 2015; Van Staa et al., 2011; Williams et al., 2007; Woodward et al., 2012
Self Management Inferred/Associated

• **↑ Responsibility** (deBeaufort et al., 2009; Fair et al., 2015; Fredericks et al., 2011; Lerret et al. 2012; Okumura et al., 2015; Ostlie et al., 2007; Rutishauser et al. 2011; Sonneveld et al., 2011; Speller-Brown et al., 2015; Van Staa et al., 2011; Weiner et al., 2011; Williams et al., 2007; Woodward et al., 2012)

• **↑ Readiness** (McMillen & Rahavan, 2009; McPherson et al., 2009)

• **↑ Independence** (Anthony et al., 2009; Disabato et al., 2015; Fair et al., 2010; Fredericks et al., 2011; Giarelli, et al., 2008; Hess et al., 2010; Jedeloo et al. 2010; Lerret et al. 2012; Maturo et al., 2015; McDonagh, Shaw & Southwood, 2006; McDonagh, Shaw & Southwood, 2006; Okumura et al., 2015; Packel et al., 2013; Shaw et al., 2006; Vijayan et al., 2009; Williams et al., 2007; Wong et al., 2010; Woodward et al., 2012)

• **↑ Adherence** (Babler et al., 2015)

• **↑ Autonomy** (Bundock et al., 2011; Crowley et al. 2011; Fair et al., 2015; Fair et al., 2010; Fredericks et al., 2011; Hays, 2015; McDonagh, Shaw & Southwood, 2006; Ostlie et al., 2007; Rutishauser et al. 2011; Vijayan et al., 2009)

• **↑ Self Advocacy** (Clariza et al. 2009; Hess et al., 2010; Moola & Norman, 2011; Okumura et al., 2015)

• **↑ Self Efficacy** (Crosby et al., 2017; Hays, 2015; Speller-Brown et al., 2015; Van Staa et al., 2011; Vijayan et al., 2009)
Self Management Inferred/Associated

- **Health literacy**  (Hess et al., 2010; McDonagh, Shaw & Southwood, 2006; Vijayan et al., 2009)

- **Activated**  (Crosby et al., 2017; Disabato et al., 2015)

- **↑ Functioning and Potential**  (Chaturvedi et al., 2009; Hilderson et al. 2009; Ostlie et al., 2007; Woodward et al., 2012)

- **↑ Navigating Skills**  (Iles & Lowton, 2010; Okumura et al., 2015; Weiner et al., 2011)

- **Improved Decision Making Skills**  (Chaturvedi et al., 2009; Fair et al., 2015; McDonagh, Shaw & Southwood, 2006; Okumura et al., 2015; Tuchman, et al., 2008; Van Staa et al., 2011; Woodward et al., 2012; Wray, 2008)

- **↑ Self-Efficacy/↑ Self-Determination**  (Crosby et al., 2017; Hess et al., 2010; Van Staa et al., 2011; Woodward, et al. 2012)
References

Al-Yateem, N. (2013). Guidelines for the transition from child to adult cystic fibrosis care, Nursing Care and Young People, 25, 29-34


Self management and adherence

- Non adherence with medications is operationalized as < 80%.
- Evidence suggests that actual adherence is ↓ than self report.
- Problems with adherence and self management leads to ↑ adverse consequences and ↓ QoL.

(Greenley et al., 2010; Hommel et al., 2009; LeLeiko et al., 2013; Rapoff, 2010)
Self Report

- Developmentally Based Skills Checklist (Annunziato et al., 2013)

- Short Form 36 Health Survey (Annunziato et al., 2013)

- Investigator developed tool to measure outcomes (Cadario et al., 2009; Chaturvedi et al., 2009)

- Satisfaction with Care (Craig et al. 2007; Valenzuela et al. 2011)

- Diabetes Knowledge Test (Pyatak et al., 2017)
References


References


References


References


Proxy Measures

- **Biomedical measurement** (Annunziato et al. (2013; Cadario et al., 2009; Crowley et al. 2011; Lane et al., 2007; Vanelli et al., 2004)
- **Preventive measures** (Bundock et al., 2011)
- **↑ Clinic visits** (Busse, et al., 2007; Craig et al., 2007; Pyatak et al., 2017; Vanelli et al., 2004)
- **Condition status; Complications** (Craig et al., 2007; Schultz et al., 2017; Prestidge et al., 2012; Pyatak et al., 2017; Van Walleghem et al., 2008)
- **Access to Adult Care** (all citations of review)
- **ED visits** (Pyatak et al., 2017)
- **↓ Morbidity and Mortality** (Findley et al., 2015; Speller-Brown et al., 2015)