

LACK OF PREPAREDNESS FOR TRANSITION OF CARE AMONG ADOLESCENT MULTIPLE SCLEROSIS PATIENTS

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DISCLOSURES

Audrey Ayres, RN has received consulting fees from Teva Neurosciences, Bayer and the MSAA.

Dr. Graves has received consulting fees from Teva Neurosciences, Bayer, Genzyme, and Pfizer.

Dr. Greenberg has received consulting fees from Amplimmune, DioGenix, Biogen Idec, Chugai, GlaxoSmithKline and the MSAA. He has equity in DioGenix and Amplimmune. He has served on the editorial board of JAMA Neurology and MediLogix. He has received grant support from the NIH, PCORI and the Guthy-Jackson Charitable Foundation.

Lana Harder, PhD and Samuel Hughes, BS have nothing to disclose.

BACKGROUND

The Maternal and Child Health Bureau (MCHB) defines children with special health care needs as:

“...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

The American Academy of Pediatrics reported in 2011 that widespread implementation of health transition supports as a basic standard of high-quality care had not been realized.

Ineffective transition has proven to negatively impact morbidity, mortality and psychosocial development.

BACKGROUND

“This {transition} process includes ensuring that high-quality, developmentally appropriate healthcare services are available in an uninterrupted manner as the person moves from adolescence to adulthood.” American Academy of Pediatrics

Patients with neurological disabilities have been underserved in relation to transition of care.

Programs making successful gains in transition of care include:

- ✓ Diabetes
- ✓ Cystic fibrosis
- ✓ Asthma
- ✓ Congenital heart disease

PEDIATRIC MULTIPLE SCLEROSIS

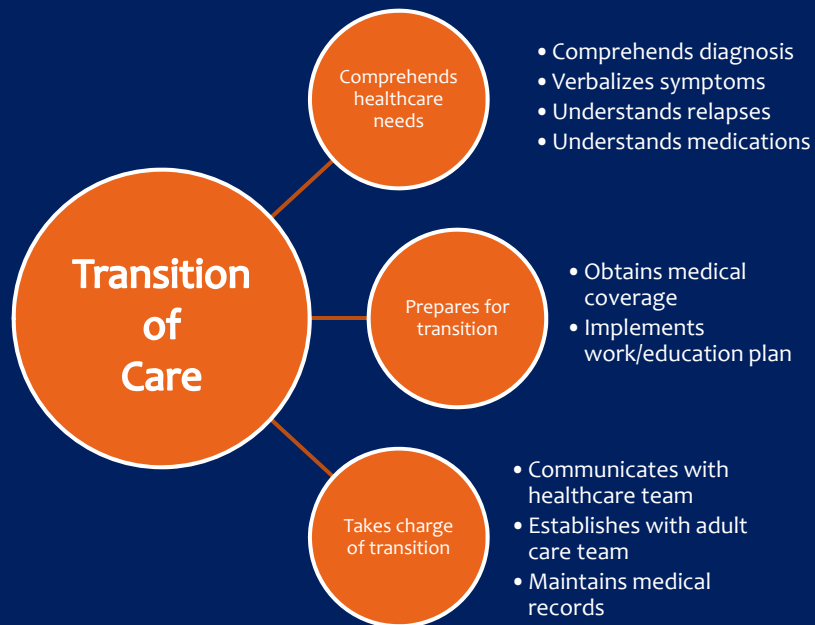
- 5-10% of multiple sclerosis (MS) patients are under age 18 at time of diagnosis
- Gender ratios are similar to adults if onset older than 10 years
- Increased annual relapse rates compared to adult-onset MS
- 42.9% of pediatric-onset MS patients transition to secondary progressive MS
- Pediatric MS patients will reach a stage of irreversible disability at an earlier age than adult-onset MS

The Problem...?

THEORETICAL FRAMEWORK: BARRIERS



THEORETICAL FRAMEWORK: OBJECTIVES

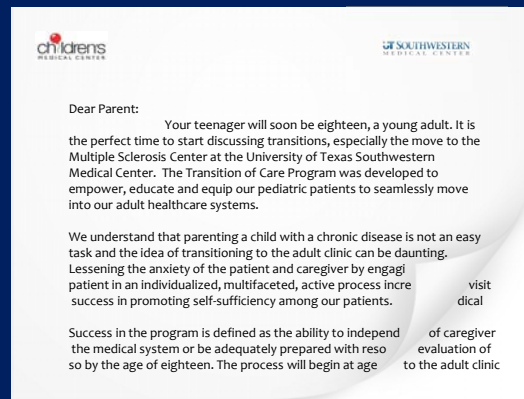


THEORETICAL FRAMEWORK: LEVELS OF TRANSITION

Objective	Level 1	Level 2	Level 3	Level 4
Knowledge of Health Needs				
Comprehension of primary diagnosis: multiple sclerosis.	States diagnosis.	Verbalizes understanding that multiple sclerosis involves central nervous system. Is able to specifically refer to the brain and spinal cord involvement.	Verbalizes understanding of neuroimmunology component of multiple sclerosis. Verbalizes that multiple sclerosis is an autoimmune mediated disease.	Demonstrates comprehension of pathophysiology by independently verbalizing disease process to the health care team.
Being prepared				
Verbalizes plan for medical coverage after the age of eighteen	Carries insurance card at all times.	Verbalizes purpose of medical coverage and understanding of necessity.	Verbalizes action plan for medical coverage after age 18 (26 if applicable).	Demonstrates action plan.
Taking Charge				
Demonstrates independence in communication with healthcare team.	Calls healthcare provider with caregiver to address concerns.	Calls healthcare provider with questions or problems with prompting. Has a separate and joint visit with healthcare provider and caregiver.	Calls healthcare provider with questions or problems independently. Brings list of questions or vocalizes concerns without prompting to the healthcare team.	Verbalizes understanding of privacy laws and patient rights.

IMPLEMENTATION

- Transition begins at age 13
 - Initial assessment
 - Develop personalized transition plan of care
 - Establish projected milestones
 - Set goals with patient and caregiver
- Full reevaluation annually
- Reinforce interventions at each visit
- At age 18, initiate an adult model of care even if there is not a physical transition
- Seamless transition by age 20



PATIENT & CAREGIVER ASSESSMENTS

Readiness Assessment

Directions: Mark an X on the table that describes your child's ability to do the following objectives independent of you.

	Never	When prompted	Independently sometimes	Independently often	Independently always
Knowledge of Health Needs:					
My child can explain his/her diagnosis.					
My child can explain his/her healthcare needs to others.					
My child knows health symptoms that need urgent (new onset neurologic symptom) medical attention.					
My child knows health symptoms that need emergent (immediate, life threatening) medical attention.					
Communication with Healthcare Team:					
My child calls for his/her doctor appointments.					
My child calls and speaks with the nurse when he/she has a problem or question.					
My child knows that he/she can see the doctor by his/herself.					

Circle the best answer for each question:

- Which of the following are NOT part of multiple sclerosis (MS)?
 - Inflammation
 - Axonal loss
 - Infection
 - Demyelination
- I take my disease modifying therapy (DMT) because
 - It helps lessen the neurologic symptoms I experience from previous multiple sclerosis (MS) relapses
 - It helps to reduce the chance of a multiple sclerosis (MS) exacerbation
 - It will cure or heal my multiple sclerosis lesions that are in my brain and spinal cord
 - My mom or dad make me take it, but I do not know why I should take it
- A pseudo-exacerbation could be caused by
 - Eating too many popsicles
 - Playing dodge ball
 - Playing video games
 - Swimming

Please circle your answer:

- My child has a plan for insurance after age 18. Yes No
- My child has post-high school plans. Yes No

Mark an X on the scale below to indicate your child's readiness to take responsibility of their medical care.

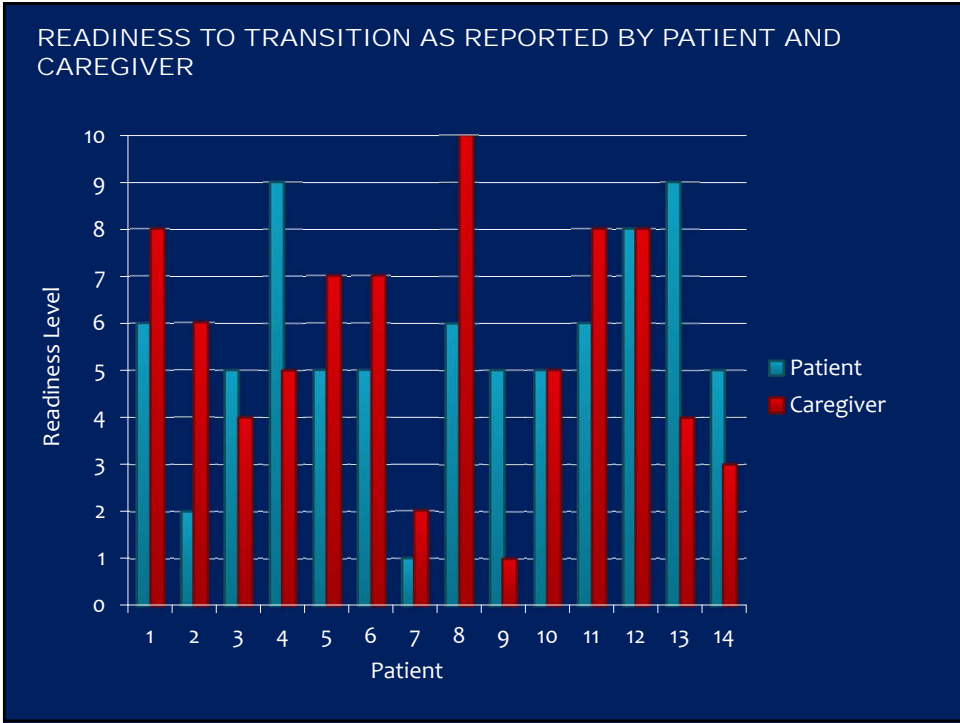
Dependent on caregiver 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Independent of caregiver

Mark an X on the scale below to indicate your anxiety level related to your child transitioning to the adult clinic at the Multiple Sclerosis Clinic at UT Southwestern.

Not anxious at all 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Very anxious

DEMOGRAPHICS

- 14 MS patients with pediatric-onset were assessed
- Racial/ethnic breakdown:
 - 7 Caucasian
 - 3 African American
 - 3 Hispanic
 - 1 Asian
- Gender breakdown:
 - 9 Female
 - 5 Male
- Age range at time of testing:
 - 13-19
- Number of days from time of diagnosis to first Transition of Care evaluation
 - Average days 884
 - Range 138 - 2057



Readiness Assessment

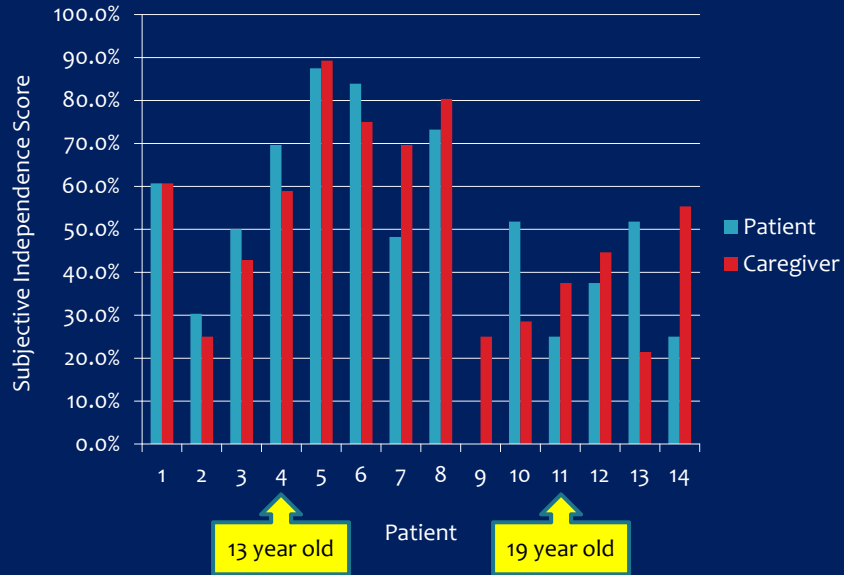
Directions: Mark an X on the table that describes your ability to do the following objectives independent of your parent or caregiver.

	Never	When prompted	Independently sometimes	Independently often	Independently always
Knowledge of Health Needs					
I can explain my diagnosis.					
I can explain my healthcare needs to others.					
I know my health symptoms that need urgent (new onset neurologic symptom) medical attention.					
I know health symptoms that need emergent (immediate, life threatening) medical attention.					
Communication with Healthcare Team					
I call for my doctor appointments.					
I call and speak to the nurse when I have a problem or question.					
I know that I can see the doctor by myself.					
Medication					
I know my disease modifying therapy (DMT).					
I call for prescription refills.					
I can list the medications I take.					
I can list the indication or reason for my medications.					
I can list the common side effects of my medications.					
I know what to do if I run out of medication abruptly.					
Financial					
I carry my insurance card every day.					

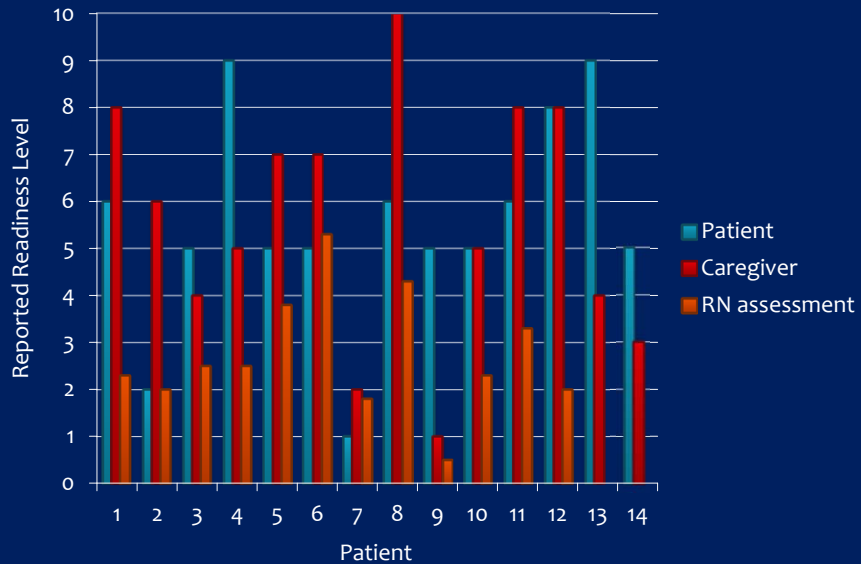
Please circle your answer:

1. I have a plan for insurance after age 18.	Yes	No
2. I have plans after I graduate high school.	Yes	No

INDEPENDENCE SCORE AS REPORTED BY PATIENT AND CAREGIVER

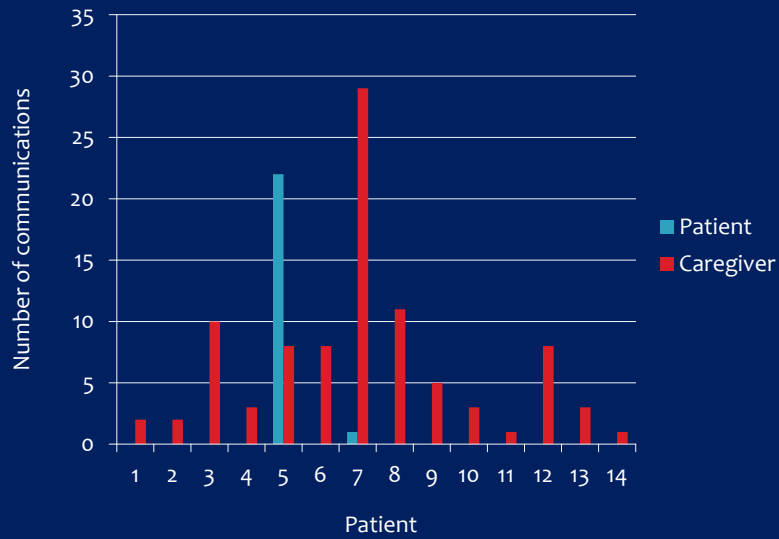


READINESS TO TRANSITION AS REPORTED BY PATIENT AND CAREGIVER

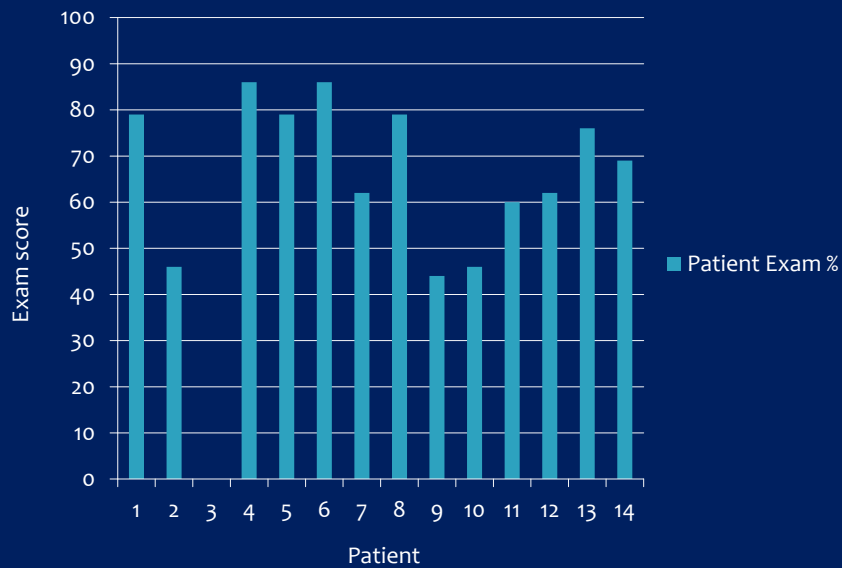


Case Example

NUMBER OF COMMUNICATIONS TO CLINIC YEAR PRIOR TO TRANSITION INITIATION



MS ANNUAL EXAM SCORES



CONCLUSION AND NEXT STEPS

- **There is an apparent disconnect between the patient, caregiver and provider in the perception of the child's ability to manage his or her own healthcare needs**
- We plan to assess children annually to include:
 - Disease knowledge
 - Readiness of patient and caregiver
 - Quality of Life assessment
 - Adherence to disease modifying therapies
 - Disease progression
 - Emergency room visits and hospitalizations
- We will develop systemized developmentally appropriate interventions
- We need to create fast-track program
- We should engage other specialties including primary care

Our Multidisciplinary Team



THANK YOU FOR LISTENING!



Questions?