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# Treatment adherence and transitioning youth in pediatric multiple sclerosis



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## KEYWORDS

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Multiple sclerosis;  
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Adherence;  
Self-management;  
Transitioning youth

## Abstract

**Background:** Transitioning youth with multiple sclerosis (MS) represent a vulnerable group to potentially poor outcomes. It is unknown how pediatric MS patients transition into adult care. **Objectives:** To describe self-management skills that include adherence to disease-modifying therapies, quality of life measures, illness perception, transition readiness and healthcare skills assessments in patients with pediatric MS and associations with clinical and cognitive outcomes. **Methods:** This is a prospective cross-sectional study at the pediatric MS center and transitional MS clinic at the University of California, San Francisco. Patients and one of their parents completed validated surveys for self-management skills. Non-adherence is defined as not taking their medication more than 20% of the time in the past 1 month. Wilcoxin matched-pairs rank test and McNemar's tests were used for comparison of patient and parent responses. Univariate and multivariate regression models were used for analyses adjusting for disease duration and socio-economic status.

**Results:** Thirty patients were enrolled with a mean ( $\pm$ SD) age of 15.8 years  $\pm$ 2.8, 53% was female and 47% Hispanic. The rate of non-adherence was 37%. The most common reason for non-adherence was forgetting to take their medication reported in 50% of patients. In adjusted regression models, higher EDSS was associated with a lower score on patient's quality of life (13 points decrease, 95% CI 6–18,  $p < 0.0001$ ), and lower healthcare skills (15 points decrease, 95% CI 5–26,  $p = 0.006$ ). Four points increase in Symbol Digit Modalities Test score was associated a 0.1 increase in transition readiness score (95% CI 0.07–0.2,  $p = 0.001$ ) and 3.9 points increase in healthcare skills scores (95% CI 1.7–6,  $p = 0.008$ ).

**Abbreviations:** QOL, Quality of life; DMT, Disease modifying therapy; UCSF, University of California, San Francisco; Ped QOL, Pediatric Quality of Life Inventory; TRAQ, Transition readiness assessment questionnaire; HCAQ, Healthcare skills assessment questionnaire; SES, Socioeconomic status; SDMT, Symbol Digit Modalities Test; EDSS, Expanded Disability Status Scale

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**Conclusions:** It is important to recognize clinical and cognitive status of pediatric MS patients as these may be critical in their ability to transition to adult care.

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## 1. Introduction

Multiple sclerosis (MS) onset occurs before age 18 in up to 10% of all MS cases (pediatric MS) (Krupp et al., 2007, S7-S12; Renoux et al., 2007, 2603-2613). These patients develop disability at a younger age, and face substantial impact on their quality of life and functional outcomes for a longer period of time (Mowry et al., 2010, 97-102).

Adherence to treatment and medication routines is a critical health maintenance skill for successful transition from pediatric to adult care. Self-management skills also involve maintaining quality of life (QOL), managing and attending doctor visits, and problem solving around health-related issues. Transitioning youth with chronic medical conditions represent a vulnerable group that may carry over their health habits into adulthood (Blum et al., 1993, 570-576). This is especially true for pediatric MS considering life-long therapies and the need for at least annual clinic visits (Lublin et al., 2014, 278-286).

Poor adherence to medication regimens is associated with worse disease outcomes in adult-onset MS (Patti, 2010, 1-9). A previous study evaluated disease modifying therapy (DMT) discontinuation rather than adherence rates in pediatric MS patients (Thannhauser et al., 2009, 119-123). Thus, adherence and how adherence and self-management skills influence clinical outcomes are unknown in young patients with MS. Identifying modifiable behaviors and predictors of poor adherence is critical to maximize best MS outcomes.

We sought to characterize self-management attributes in pediatric MS including transitioning care into adulthood. We used validated questionnaires completed by the patient and one of the parents to identify possible discordance between reports. We also describe associations between self-management and clinical outcomes in pediatric MS that may be important to develop future interventions in this age group.

## 2. Methods and subjects

### 2.1. Study design

This is a cross-sectional study of prospectively enrolled patients from the University of California San Francisco (UCSF) pediatric MS center and MS transition clinic. The research protocol was approved by the UCSF Committee on Human Research and written informed consent was obtained from parents and patients aged 18 years and older. Assent was also obtained from all patients younger than 18 years of age.

### 2.2. Study subjects

Inclusion criteria include: 1) a diagnosis of MS according to the International Pediatric Multiple Sclerosis study group

criteria (Krupp et al., 2013, 1261-1267), 2) age at enrollment between 12 and 23 years with disease onset before 18, 3) patients with at least 2 prior visits at the UCSF pediatric and/or transitional MS clinics, and 4) taking a self-administered DMT for at least 3 months. We chose this age group because the process of preparing youth with chronic health conditions and disabilities for the transition to adult care typically starts in early adolescence (American Academy of Pediatrics and American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine, 2002, 1304-1306).

Exclusion criteria include a diagnosis of developmental disorders that could interfere with the patient's ability to follow instructions and cognitive testing. Patients or parents who were not fluent in English were also excluded, as questionnaires used were not validated in other languages.

### 2.3. Questionnaires completed

The patient and one parent completed the Pediatric Quality of Life Inventory (Ped QOL) (Nortvedt et al., 1999, 1098-1103), Brief Illness Perception Questionnaire (IPQ) (Broadbent et al., 2006, 631-637) and an adherence questionnaire (Bruce et al., 2010, 112-120) at the time of their routine clinic visits (Supplementary Table 1). Patients additionally completed the healthcare skills related questionnaire, which includes the Transition readiness assessment questionnaire (TRAQ) (Sawicki et al., 2011, 160-171). Parents also completed a health care skills assessments questionnaire (HCAQ) (Hackworth and McMahon, 1991, 69-85) (Supplementary Table 1). We defined non-adherence as missing DMTs more than 20% of the time in the past month (Lu et al., 2008, 86-94). We selected a 1 month time period to avoid recall bias (Lu et al., 2008, 86-94). Parents self-reported ethnicity and completed socio-economic status (SES) questionnaires. SES was calculated using participating parent and partner's education level, employment, and total household income (Thakur et al., 2013, 1202-1209). This information was dichotomized into low versus medium/high SES.

### 2.4. Clinical and demographic data

Patients underwent brief neuropsychological evaluation with the verbal form of the Symbol Digit Modalities Test (SDMT) at the time of their visit (Charvet et al., 2014, 79-84). We collected clinical data including the presence of at least one relapse in the past year, Expanded Disability Status Scale (EDSS), and disease duration at the time of enrollment by medical records review.

### 2.5. Data management and statistical analysis

Questionnaires completed on paper forms were entered into REDCap Software-Version 5.5.11-© 2013 Vanderbilt University

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