Cleveland Clinic
Neurological Institute

Multiple Sclerosis Care and Transgender Persons: A Case Study and Recommended Best Practice Guidelines

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INTRODUCTION

Recent nationwide surveys have highlighted significant disparities in healthcare for transgendered persons, who are currently considered a "priority population."[1] The gaps in quality healthcare are often attributed to internalized stigma of providers and lack of training in addressing transgender-specific health care needs in medical school/residency programs.[2]

Although best practice guidelines exist for providers in the fields of primary care and obstetrics and gynecology, guidelines for other specialty providers, such as MS neurologists, are lacking. There is little empirical evidence surrounding the intersection between cross-sex hormone replacement therapy (HRT), neuroimmunologic processes, and disease-modifying treatments (DMTs). These guidelines are also lacking with regard to culturally-sensitive communication between patient and providers (preferred names, pronouns, etc.) and coordination between medical and allied providers to facilitate high-quality MS care for an underserved population.

This case study describes an adolescent/young adult patient receiving services at a comprehensive care center (CCC) for MS. The patient initially presented as a biological female and later identified as transgendered male (female-to-male; FTM). The following includes a comprehensive medical and psychosocial history along with best practice guidelines for serving a transgendered population with a multidisciplinary approach in a CCC for MS.

MS DISEASE SUMMARY

Date of MS Symptom Onset: 5/2012

May 2012: Presented to local emergency department (ED) with vision difficulties, paresthesia and numbness in legs and feet upon walking. No testing or therapy. Symptoms improved but did not return to baseline.

September 2012: Presented to local ED with clinical relapse symptoms. Treated with intravenous methylprednisolone sodium succinate (IVMP) for 5 days and symptoms gradually improved. Patient underwent neurological testing: MRI, CSF, and VEP.
Brain MRI (9/2012): Classic changes of MS involving periventricular white matter, corpus callosum, and the brainstem (enhancing lesions present).

October 2012: Diagnosis of Relapsing-Remitting MS confirmed

March 2013: First appointment at CCC to confirm definite MS diagnosis. Presented with diplopia. Patient admitted to ED and treated with 5 days of IVMP resulting in brief relief of symptoms.

March 2013 – May 2015: Patient hospitalized for multiple non-MS related symptoms (e.g., dehydration/gastrointestinal complaints), as well as MR-related neurologic symptoms.
Previous Disease Therapies: Glatiramer acetate (discontinued due to side effects), dimethyl fumarate (discontinued due to side effects), & multiple courses of IVMP

Current MS Disease Course: Relapsing-Remitting MS
Current Disease Modifying Therapy: Interferon beta-1a
Current Brain MRI (1/2015): One new T2 lesion in left periatrial region. Other supratentorial and infratentorial white matter lesions are stable.
Current Cervical/Thoracic Spine MRI (12/2014): Multiple non-enhancing lesions.
Long-term symptoms: Nausea, diplopia, and L'hermittes.

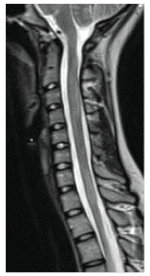


Image 1: Stir Image of the Cervical Spinal Cord in 12/2014

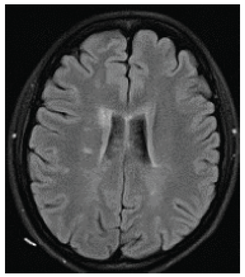


Image 2: Flair Image of the Brain in 1/2015

CASE STUDY

Psychosocial History
**Patient identifies as a gender neutral and prefers use of gender neutral pronouns. Thus, patient will be referred to as "they" or "their" throughout the poster.*

Patient is biological female, identifies as transgender male and occasionally as gender fluid. Patient is the only child of biological parents. Parents divorced when the patient was four years of age was subsequently raised primarily by mother and maternal grandmother in rural Midwest. Family dynamics were marked by substance abuse, neglect and emotional abuse. Patient completed nine years of formal education and dropped out of school at the age of 16. Attempts to complete coursework via online programming were unsuccessful due to patient's perceived cognitive difficulties. There is no meaningful/gainful employment history. Support is limited to romantic partner, immediate family members and online gay, lesbian, and transgender community.

Patient described non-gender conforming attitudes beginning during middle childhood and began experimenting with outward expressions of male and female presentations in dress as an early adolescence. The patient reported feeling ostracized and verbally criticized by school-age peers and extended family members for decision to live as a male. Patient endorsed significant depressive and anxiety symptoms likely related to lack of support for gender exploration, and engaged in self-injurious behaviors and suicidal thoughts as a means to cope. Patient also endorsed dating male and female partners during adolescence, and has self-identified as a bisexual since the age of 13.

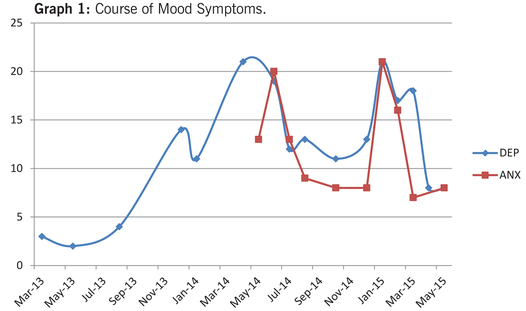
The patient has been romantically involved with male partner for approximately three years, and currently cohabitates with partner. The patient's partner is active in coordinating medical care and attending appointments, often acting in parental role

Psychological Assessments
Neuropsychological testing: Formal neuropsychological testing indicated the patient's general level of ability to be in the low average-average range. Deficiencies noted in complex visual scanning and verbal rote learning. Attention/concentration within normal limits. Testing indicated cognitive slowing due to MS-related demyelination, emotional distress, and significant sleep disturbances.

Personality testing: Patient administered the Minnesota Multiphasic Personality Inventory-Restructured Form and Sixteen Personality Factor Questionnaire. Somatic complaints endorsed were specific to neurological symptoms, and preoccupation with perception of poor health. Profile indicated a pervasive history of mood disturbances, self-criticism, and low frustration tolerance. Profile also highlighted the patient's persecutory ideations, suspicion of others' motives, social awkwardness, and introversion.

Symptom measures

Graph 1: Course of Mood Symptoms.



Depression symptoms were measured by the Patient Health Questionnaire 9-item (PHQ-9) scale (score of 5-9: mild depression, score of 10-14: moderate depression, score of 15-19: moderate-to-severe depression, score of 20-27: severe depression). Anxiety symptoms were measured by the Generalized Anxiety Disorder 7-item (GAD-7) scale (a score of 10 or higher indicates a possible anxiety disorder).

Patient began working with Behavior Medicine team in May 2014, and attended in a total of 25 outpatient psychotherapy appointments across two providers (doctoral-level health psychology fellows). The patient completed depression and anxiety measures approximately once per month. Following significant increase in mood symptoms in February 2015, the patient has attended weekly outpatient therapy sessions.

Course of Psychotherapy
Patient presented to outpatient psychotherapy reporting long-standing depressive and anxiety symptoms. Patient reported chronic history of suicidal ideations (one suicide attempt) and emotional lability. Initial psychotherapy focused on improving coping skills for mood symptoms and interpersonal disputes through use of cognitive-behavioral strategies. Exploration of gender identity was an evolving focus of therapy. The patient was on citalopram 10 mg. The following psychotherapy themes have emerged:

Gender Identity Exploration/Affirmation: 'Coming out' experience to family; transition to live full-time as a male; exploring medical and psychological issues associated with gender affirmation treatment (e.g., cross-sex HRT); referral to endocrinology clinic (not pursing HRT at this time); relationship between gender identity-related stress and somatic (MS/non-MS related) symptoms

Interpersonal Difficulties: Chronic unhealthy interpersonal dynamics with family-of-origin; learning assertive communication strategies with partner/mother; cultivating independence within romantic relationship

Adjustment to MS: Discussion of relationship between MS exacerbations and psychological stress; needle phobia; coping with functional losses (cognitive and physical)

CROSS-SEX HORMONAL THERAPY AND MS

As DMTs have evolved over the last two decades to reduce inflammatory processes and clinical disability, the role of sex hormones as a potential therapy for MS have emerged[4]. The use of testosterone as an experimental neuroprotective treatment for MS has recently been explored[5], and suggestive of a neuroprotective quality; however, anti-inflammatory effects are not evident[6].

The use of testosterone in biological female patients diagnosed with MS for the purpose of cross-sex HRT remains unclear. Testosterone dosage levels for the purpose of cross-sex HRT often differ in amount than those used in clinical trials. In a previously reported case study of a fully transitioned (FTM) transgender male with relapsing-remitting MS, significant clinical relapses and disability continued following surgical intervention and long-term testosterone therapy[7]; however, it is unclear if steady doses of testosterone both before and after surgical transition from FTM precipitated the accumulating disability.

BEST PRACTICE FOR CARE OF THE TRANSGENDER MS PATIENT IN A MS CCC

1. Emphasis on patient-provider relationship:
   a. Honor the patient's preferred name, pronouns, and terminology to describe gender identity
   b. Be respectful and welcoming to patient's preferred loved one/friend during appointments
   c. Assurance of and limits to confidentiality

2. Creating an inclusive culture:
   a. Modify patient intake forms by including items reflective of sex-assigned-at-birth and current gender identity3
   b. Advertise non-discriminatory policy of CCC throughout public areas and exam rooms
   c. Provider training to all providers and support staff regarding sensitivity to transgender issues

3. Encourage patient to participate in general screening and preventative care, consistent with sex-assigned-at-birth, with primary care provider.

4. Assess current and history of sexual health practices consistent with sex-assigned-at-birth (to aid in selection of appropriate DMT):
   a. Assess need for referral to OB-GYN (and possible need for contraceptives)
   b. Identify the biological sex of any sexual partner(s) and assess risk for pregnancy

5. Create an open dialogue between neurologist and provider regarding current knowledge of the interplay between use of cross-sex HRT and MS disease activity. Management of a FTM transgender will likely require a case-by-case approach, and consider the following factors:
   a. Dosage and timing of testosterone during the transition period (initiation and maintenance phases)
   b. Stability of the patient's disease activity and clinical symptoms
   c. More frequent follow-up appointments and MRIs to monitor lesion activity

6. Establish working relationships and collaborate closely with other relevant medical providers involved in transgender persons, such as endocrinology and OBGYN.

7. Screen regularly for mood symptoms, such as depression and anxiety, as these symptoms are more prevalent in MS population and likely to be even more salient within LGBT individuals. Refer to behavioral medicine, as needed.

8. Provide referral information for local MS support groups specific to LGBT issues sponsored by the National Multiple Sclerosis Society.

*References available upon request.