Abstract

Background
The COVID-19 pandemic has raised concerns for increased risk of infection in patients with multiple sclerosis (MS) and disrupted their routine MS care.

Objectives
The aim of this study is to characterize the extent of MS patients’ perceptions of risk and adherence to care during the pandemic.

Methods
A survey was emailed to patients from a large MS center in New York City during the local peak of the pandemic to assess perceptions of infection risk and adherence to MS care including appointments, laboratory studies, MRIs, and taking disease-modifying therapies (DMT).

Results
529 patients from the MS center responded to the survey during two-weeks in April 2020. Patients collectively showed concern about becoming infected with COVID-19 (88%) and perceived a higher infection risk because of having MS (70%) and taking DMTs (68%). Patients frequently postponed appointments (41%), laboratory studies (46%), and MRIs (41%). Noncompliance with DMTs was less common (13%). Decisions to alter usual recommendations for care were made by the patient more often than by the provider regarding adherence to appointments (68%), laboratory studies (70%), MRI (67%), and DMTs (65%). Degree of concern for infection was associated with adherence to appointments (p=0.020) and laboratory studies (p=0.016) but not with adherence to MRI and DMTs. Thirty-five patients reported being tested for COVID-19, of whom fourteen reported a positive test.

Conclusions
Patients with MS were highly concerned about becoming infected during the local peak of the COVID-19 pandemic. Behaviors that deviated from originally recommended MS care were common and often self-initiated, but patients were overall compliant with continuing DMTs.