

# US health insurance is an obstacle to disease-modifying treatments in MS

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In 1993, the first disease-modifying therapy (DMT) specifically for relapsing-remitting multiple sclerosis (RRMS) was introduced, and an untreatable disease became treatable. The US Food and Drug Administration now has approved 14 DMTs in 8 classes with different mechanisms of action, administration routes, and side effects.<sup>1</sup> This therapeutic palette allows neurologists to control RRMS in most patients.

The transformational achievement of MS DMT, however, has come with a great price. In the United States, prices of MS DMTs have skyrocketed in recent years. The average wholesale price of new and old therapies now is ~\$65,000 a year and prices continue to rise.<sup>2</sup> In response, insurance companies and specialty pharmacies create restrictions limiting access to these medications, disrupting (or at least, strongly influencing) the care physicians provide their patients with MS.<sup>3</sup>

In this issue of *Neurology*®, Wang et al.<sup>4</sup> report on a survey conducted in 2014 of 6,662 people with MS, designed to explore the relationships between insurance coverage and DMT use. The survey was sent to 12,492 active members of the North American Research Committee on MS (NARCOMS), a voluntary self-report registry; 7,601 (60.9%) completed the survey and 6,662 (87.6%) of these answered all questions related to health insurance. Thus 53.3% returned a completed survey and were eligible for analysis. Given the large size of the survey, this seems to be a robust response rate. Nearly all (98.5%) reported having some form of medical insurance, with 42.3% having only private insurance, 22.3% only public, 20.4% private and public, and 14.9% public with a supplemental. While most reported that their insurance had not changed from the preceding year, 22.1% reported that they had worse coverage.

Most respondents were taking a DMT (69.2% for all respondents and 80.6% for the RRMS subset). Among respondents not taking a DMT, most noted that this decision was based on personal decision or physician recommendation. However, 6.1% of all respondents and 9.2% with RRMS were not taking a DMT because of financial or insurance reasons. Compared with those taking a DMT, those not

taking a DMT tended to be older, unemployed, and male, and had lower incomes, longer disease duration, and more severe disability. Remarkably, 24.7% of those taking a DMT used a pharmaceutical-supported program that provided their drug at no cost or a heavily discounted price. In the preceding year, 7.8% of respondents experienced some obstacle to insurance coverage of a DMT, most commonly denial of coverage. Thus, a small but important number of people were not taking a DMT because of financial reasons, 24.7% required a drug assistance program, and 7.8% recently encountered obstacles to insurance coverage of a DMT.

There are limitations to the study. This investigation used a self-report survey of a subset of people registered with NARCOMS. It therefore has all of the potential pitfalls of self-reported surveys. It also had a relatively low percentage (53.3%) of respondents who returned the survey with all questions about health insurance answered. In addition, the NARCOMS registry is not a random sample of people with multiple sclerosis (MS). The survey did not capture information about the percentage of respondents who rely on copay support programs, which represents another cost that pharmaceutical companies absorb. The survey also did not assess whether high deductibles influenced DMT use, a financial burden for individuals taking a DMT. Despite these limitations, this study provides insights into the challenges confronting the use of MS DMTs in the United States.

The survey provides no information on health care coverage and DMT use outside the United States. This would be an illuminating comparison. Access to treatment varies remarkably for people with MS in the European Union and United States.<sup>5</sup> In Italy, the United Kingdom, and other EU countries, the government pays the full price of DMTs. The provision of full coverage and availability of organized MS centers may increase adherence to DMTs and eliminate the kinds of access challenges experienced by people with MS in the United States.<sup>6</sup>

This survey suggests that nearly all people with MS in the United States have some form of insurance

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coverage. While this is encouraging, 1 in 5 of the respondents indicated that their insurance coverage had worsened over the preceding year. Over 60% of respondents relied in part or entirely on some form of public insurance, presumably Medicare or Medicaid. This points to the importance of public insurance in providing care to people with MS in the United States.

The survey suggests problems related to MS DMT use in the United States. Despite the widespread availability of insurance coverage, a small number of patients with RRMS cannot take a DMT for financial or insurance reasons. About 25% of those taking a DMT rely on programs supported by the pharmaceutical industry that provide free or heavily discounted drug. Almost 8% of respondents encountered some challenges related to insurance coverage of their DMT. This may underestimate the number of insurance policies that restrict access to MS DMTs, since this study only focused on the 6 months preceding the survey and most of the respondents were on a previously approved DMT. For those encountering coverage challenges, their physicians often successfully appealed the decisions of insurance companies. This is to the credit of their physicians, but the survey does not capture the large amount of unreimbursed time spent by neurologists and their staffs appealing denials of coverage by insurance companies, which is a frustrating and expensive part of treating people with MS.<sup>3</sup>

US neurologists need to speak out about the unfettered rise of MS DMT prices and the obstacles to care created by insurance companies and specialty

pharmacies. The advancements in the treatment of MS have been remarkable. However, we have much to do in the United States to ensure that all people with RRMS receive the full benefits of the transformational advances in the treatment of MS.

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## DISCLOSURE

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