

A survey of risk tolerance to multiple sclerosis therapies

Robert J. Fox, MD, Carol Cosenza, MSW, Lauren Cripps, et al.

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Correspondence

Dr. Fox
foxr@ccf.org

Study objective and summary result

This study explored the tolerance of patients with multiple sclerosis (MS) to 6 risks associated with current disease-modifying therapies (DMTs), and it found that tolerance levels vary widely among patients and for different risks.

What is known and what this paper adds

The last 2 decades have seen the introduction of several new DMTs for MS, but relatively few studies have explored the risk tolerance of patients with MS in the context of current treatment options. This study provides some elucidation on that topic.

Participants and setting

This study contacted 3,755 individuals with MS through the North American Research Committee on MS Registry and asked them to complete an online survey that was available from March 3, 2016, to April 8, 2016. A link to the survey was also publicly available on the National MS Society's website from March 17, 2016, to April 16, 2016.

Design, size, and duration

The survey collected basic demographic and clinical information and gauged the participants' tolerance levels to 6 potential risks associated with a hypothetical therapy that reduces relapse rates by 50% and slows disease progression by 30%. The 6 risks were skin rashes, infections, kidney injury, thyroid injury, liver injury, and progressive multifocal leukoencephalopathy (PML), all of which are potential risks associated with existing DMTs for MS. Risk tolerance levels were gauged based on the highest acceptable odds of each risk.

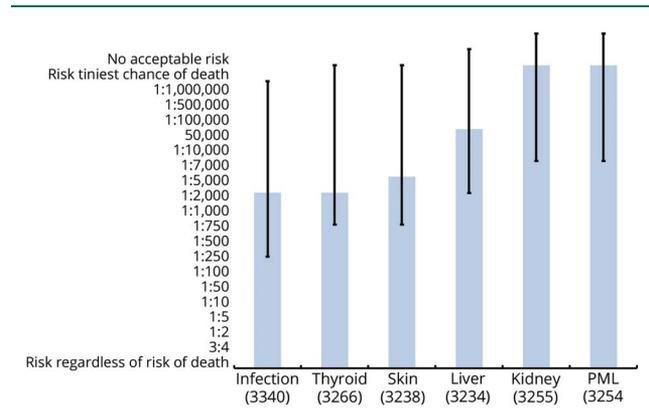
Primary outcome measures

The primary outcomes were the highest acceptable odds for the 6 risks.

Main results and the role of chance

This study collected responses from 3,371 patients with MS. The median acceptable odds ranged from 1:1,000,000

Figure Median acceptable odds for the 6 risks (solid bars) with interquartile ranges (capped lines)



for PML and kidney injury to 1:1,000 for thyroid injury and infections.

Bias, confounding, and other reasons for caution

The reported risk tolerance of participants may be biased by therapies they are already taking.

Generalizability to other populations

This study recruited patients residing in the US. This may limit the international generalizability of the results.

Study funding/potential competing interests

This study was funded by the National MS Society. Some authors report receiving consulting fees from Oxford University Press and professional societies and receiving research support, consulting fees, and committee appointments from various healthcare companies. Go to Neurology.org/N for full disclosures.

A draft of the short-form article was written by M. Dalefield, a writer with Editage, a division of Cactus Communications. The corresponding author of the full-length article and the journal editors edited and approved the final version.

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