



## Sharing notes with patients: A review of current practice and considerations for neurologists

**Nitin K. Sethi, MD:** I read with interest the Yu et al.<sup>1</sup> commentary on sharing office visit notes with patients. I often read aloud the last office visit notes to my patient at the time of the follow-up visit. I begin this by saying “this is what I documented when I last saw you. Please correct me if I got anything wrong in your history.” I have found this helpful in 2 ways. One, it helps to refresh the history, assessment, and plan in my own mind; and second, it helps engage the patient and accompanying caregiver in his or her care. My experience with this exercise has been a mixed bag. Some patients compliment me for documenting a comprehensive history, while others berate me for getting their hand dominance wrong, or documenting their alcohol intake or use of illicit drugs. Medicine is a science and you call a spade a spade. Alcoholism is not synonymous with social drinking and I fear that physicians would have to water down their notes just to avoid offending the patient. A physician’s office notes should be an accurate, objective, and nonjudgmental documentation of the patient rather than a politically correct one. Finally, a physician should never forget that the office note is a medico-legal document, one that can be produced in court and at times used against him or her.

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**Disclosures:** N. Sethi serves as Associate Editor of *The Eastern Journal of Neurology*.

**Authors Respond: Melissa M. Yu, MD; Allison Weathers, MD; Allan D. Wu, MD; David A. Evans, MBA:** We thank Dr. Sethi for his comments on our article<sup>1</sup> and for sharing his personal experience with open notes. We agree with his comments and want to emphasize that we do not advocate for watering down clinical documentation. The integrity of the clinical note for its primary purpose is paramount. In addition, although patients may be upset in the short term, calling a spade a spade when it comes to substance use, and the patient’s viewing the documentation in the privacy of his or her own home may allow the patient to eventually overcome denial and take action. If a note is felt to be particularly sensitive, the provider should have the option to refrain from releasing the note to the patient as well.

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1. Yu MM, Weathers AL, Wu AD, Evans DA. Sharing notes with patients: a review of current practice and considerations for neurologists. *Neurol Clin Pract* 2017;7:179–185.

## Rehabilitation in multiple sclerosis: Commentary on the recent AAN systematic review

**Jodie K. Haselkorn, MD, MPH; Christina Hughes, MD; Alexander Rae-Grant, MD; Lily Jung Henson, MD, MMM; Christopher T. Bever, MD, MBA; Albert C. Lo, MD, PhD; Theodore R. Brown, MD, MPH; George H. Kraft, MD, MS; Gary Gronseth, MD; Melissa J. Armstrong, MD, MSc; Pushpa Narayanaswami, MBBS, DM:** We thank Sutliff et al.<sup>1</sup> for their commentary on our systematic review (SR), “Summary of comprehensive systematic review: Rehabilitation in multiple sclerosis.”<sup>2</sup> We would like to make several points in response. (A more extensive response is available at [Neurology.org/cp](http://Neurology.org/cp).)

First, contrary to their comment that our panel<sup>2</sup> “lacked specialist diversity,” the panel included multiple sclerosis (MS) experts, rehabilitation experts, non-MS neurologists, and guideline methodologists. Furthermore, the National Multiple Sclerosis Society was part of the process.<sup>2</sup> Physical and occupational therapists, speech/language therapists, and exercise physiologists were not included; this reflects the guideline development process at the time. Nevertheless, this was an SR,<sup>2</sup> not a clinical practice guideline (CPG). An SR makes conclusions based on available evidence, whereas CPGs make practice recommendations. The CPG process lends itself to expert formal consensus; the SR does not. The conclusions of our SR<sup>2</sup> would have been the same even with the inclusion of other experts because they are based on the American Academy of Neurology (AAN) risk of bias assessment of each study and not expert opinion.

Second, we have highlighted methodologic limitations of the rehabilitation literature in our recommendations for future research.<sup>2</sup> We do not deem it appropriate to blame the risk of bias assessment for failure to identify high-level studies in our SR.<sup>2</sup> Instead of setting a lower bar for the quality of studies and accepting weaker evidence to inform practice, the field of rehabilitation should be challenged to improve the science and obtain high-quality evidence.

Third, we recognize the lag between the search in 2013 and the SR<sup>2</sup> published in 2015, which is a common issue for most SRs/CPGs due to the time it takes to develop them. Despite this, based on the quality of studies identified in the previous 2 searches,<sup>2</sup> the likelihood of finding high-quality evidence to drive recommendations was low.

Fourth, Sutliff et al.<sup>1</sup> provide a table of studies that were “not included” in our SR.<sup>2</sup> This is inaccurate. Because of word count limitations, only studies that drove conclusions were discussed in the executive summary.<sup>2</sup> At least 5 of these “excluded studies”<sup>3–7</sup> are included in the full SR online.<sup>2</sup> Hebert et al.<sup>8</sup> was excluded because vestibular rehabilitation was not within the scope of our SR.<sup>2</sup> Several others<sup>9</sup> were published after our SR<sup>2</sup> or were narrative reviews.<sup>10</sup> Finally, Sutliff et al.<sup>1</sup> raise a concern regarding reimbursement due to misinterpretation of this review. We emphasize that this is an SR<sup>2</sup> without practice recommendations.

We solicited comments on our SR<sup>2</sup> twice from the AAN MS section and responded to all comments, many of which were brought up by Sutliff et al.<sup>1</sup> (table e-1 available at [Neurology.org/cp](http://Neurology.org/cp) in full-length response). A process to engage the SR authors and the AAN Guideline Development, Dissemination, and Implementation subcommittee leadership prior to publication of their commentary would have conclusively clarified several of the concerns from Sutliff et al.<sup>1</sup> CPGs/SRs are reviewed every 3 years to evaluate new literature that will change the published conclusions/recommendations. When this process is undertaken for the MS Rehabilitation SR,<sup>2</sup> newer AAN guideline development methodology will be utilized to include perspectives from specialty societies, patients, other health care professionals, and public comments.

US Veterans Health Administration and University of Washington (JKH), Seattle; Evergreen Health Rehabilitation Services (CH), Kirkland, WA; Cleveland Clinic and Case Western Reserve University (AR-G), Cleveland, OH; Swedish Neuroscience Institute (LJH), Seattle, WA; University of Maryland School of Medicine and VA Maryland Health Care System (CTB), Baltimore; Brown University, Providence VA Medical Center, Providence, RI and Mount Sinai Rehabilitation Hospital (ACL), Hartford, CT; Evergreen Neuroscience Institute (TRB), Kirkland, WA; University of Washington

Supplemental Data

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1. Sutliff MH, Bennett SE, Bobryk P, et al. Rehabilitation in multiple sclerosis: commentary on the recent AAN systematic review. *Neurol Clin Pract* 2016;6:475–479.
2. Haselkorn JK, Hughes C, Rae-Grant A, et al. Summary of comprehensive systematic review: rehabilitation in multiple sclerosis. *Neurology* 2015;85:1896–1903.
3. Schulz KH, Gold SM, Witte J, et al. Impact of aerobic training on immune-endocrine parameters, neurotrophic factors, quality of life and coordinative function in multiple sclerosis. *J Neurol Sci* 2004;225:11–18.
4. Cattaneo D, Jonsdottir J, Zocchi M, Regola A. Effects of balance exercises on people with multiple sclerosis: a pilot study. *Clin Rehabil* 2007;21:771–781.
5. Dettmers C, Sulzmann M, Ruchay-Plossl A, Gutler R, Vieten M. Endurance exercise improves walking distance in MS patients with fatigue. *Acta Neurol Scand* 2009;120:251–257.
6. Petajan JH, Gappmaier E, White AT, Spencer MK, Mino L, Hicks RW. Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Ann Neurol* 1996;39:432–441.
7. Solari A, Filippini G, Gasco P, et al. Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. *Neurology* 1999;52:57–62.
8. Hebert JR, Corboy JR, Manago MM, Schenkman M. Effects of vestibular rehabilitation on multiple sclerosis-related fatigue and upright postural control: a randomized controlled trial. *Phys Ther* 2011;91:1166–1183.
9. Chruzander C, Gottberg K, Ytterberg C, et al. A single-group pilot feasibility study of cognitive behavioural therapy in people with multiple sclerosis with depressive symptoms. *Disabil Rehabil* 2016;38:2383–2391.
10. Motl RW, Sandroff BM. Benefits of exercise training in multiple sclerosis. *Curr Neurol Neurosci Rep* 2015;15:62.

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