THERAPEUTIC ADVANCES in
Neurological Disorders

Letter to the Editor

Perspective: Industry–patient relationships for the promotion of pharmaceutical agents

Meredith A. Bryarly*, Michael A. Rubin* and Olaf Stuve

Ther Adv Neurol Disord

2023, Vol. 16: 1–3

DOI: 10.1177/17562864231207560

Keywords: conflict of interest, medications, medical ethics, neurologists, patients, pharmaceutical industry, physicians

Received: 21 December 2022; revised manuscript accepted: 25 September 2023.

Correspondence to:
Olaf Stuve
Department of Neurology, University of Texas Southwestern Medical Center, 6000 Harry Hines Blvd, Dallas, TX 75390-8813, USA

Neurology Section, VA North Texas Health Care System, Dallas, TX, USA
olaf.stuve@utsouthwestern.edu

Meredith A. Bryarly
Michael A. Rubin
Department of Neurology, University of Texas Southwestern Medical Center, Dallas, TX, USA

Peter O'Donnell Brain Institute, University of Texas Southwestern Medical Center, Dallas, TX, USA

* These authors contributed equally

Dear Editor

We wish to bring an emerging ethical challenge to the attention of your readers. While it is well recognized that financial relationships between clinicians and the pharmaceutical industry may serve interests that present substantial conflicts, financial relationships between industry and patients are less understood regarding their potential impact on patient care and prescribing practices. We have had a recent patient care experience that illustrates the potential ethical complexities of commercial relationships between the pharmaceutical industry and patients.

One of the authors recently cared for a patient with a diagnosis of Lambert-Eaton myasthenic syndrome who underwent conventional treatments with an acceptable clinical response. A few months into the treatment course, the patient started an investigational agent as part of an open-label study. After the patient completed the open-label study, the manufacturer continued to provide the medication at no cost temporarily. The patient believed the medication improved their symptoms and after the no-cost period expired, the patient subsequently requested the medication to be continued to be prescribed through a tertiary medical center in North Texas. The patient then continued conventional treatment in addition to the newly approved treatment for almost 4 years, and there were no signs of disease on neurological examination. Subsequently, the subject of attempting to taper back either treatment was broached at a clinic visit. Since the patient had been well controlled on conventional treatment alone and had symptoms with missing doses in the past, the new agent was felt to be the best agent to first taper. Following this discussion, the patient filed a formal complaint with the medical center administration where they were receiving care, asking to be assigned to another neurologist. Specifically, the patient was upset by the suggestion of tapering back the newer agent. The severity of the response to the clinician's suggestion was out of proportion to usual disagreements over therapeutic choices.

During subsequent conversations with the patient, the patient volunteered that they participated in advisory panels for the new agent in early 2018 while enrolled in the open-label study mentioned above. For their participation in these advisory panels, they received monetary compensation. Later, the company employed and paid them as a speaker and patient advocate for the product. The patient refused to provide further specifics regarding their relationship with the company, stating that they had signed a non-disclosure agreement. These relationships between patients and the pharmaceutical industry can be confirmed by publicly accessible records.

The scenario described above raises several ethical concerns. While the pharmaceutical industry and patients have interests that intrinsically overlap, namely the availability of safe and effective therapeutic interventions; close associations between industry and patients are highly asymmetrical and have the potential to assume an exploitative nature for the patient. Patients may engage in such a relationship because of monetary gain, access to pharmaceutical agents, attention from peers, or a combination of these factors. The very illnesses that patients are afflicted with may make them vulnerable to the influence of pharmaceutical companies.

As the traditional paradigm of a patient deciding to follow or disagree with a clinician's recommendation has been replaced with the shared medical decision-making model, many patients are now educated medical consumers who are accustomed to suggesting or requesting certain treatments be provided. They also frequently encounter pharmaceutical marketing that will influence their perspective just as a clinician may be influenced by media and personal relationships with the industry.

In the patient–physician relationship described above, the patient was financially compensated by a pharmaceutical company for promoting an expensive product at patient group meetings for which substantially less expensive alternatives are available. The conflict of interest appears apparent: The patient receives monetary compensation for promoting a product they are receiving and perceive to be beneficial. However, the patient may only be of significant value to the pharmaceutical company if they are continuing to consume the product and can publicly attest to its benefits. Consequently, the patient will only receive monetary compensation from the pharmaceutical company if they continue to be prescribed the product.

There is another potential effect of a direct pharmaceutical industry-to-patient relationship: An effect on the behavior of other patients subjected to information provided to them by a patient compensated by the pharmaceutical company. There is ample evidence that patients are very susceptible to information provided to them by other patients.[1–4] As most patients who will lecture presumably are not physicians, or have substantial medical or scientific training, the quality of the information they convey to their peers will be somewhat limited and likely biased. Currently, such patients have no obligation to disclose any conflict of interest with the manufacturer of a drug to other patients, or their providers.

While patients may learn about conflicts of interest of their clinicians, there are no such regulations regarding patient advocates. In many countries, there are public reporting programs that list payments and other gifts from drug and medical device companies to doctors.[5] In addition, many healthcare systems and medical centers require annual disclosures of conflicts of interest of their doctors, and this information is then displayed on their websites.[5] Similar requirements can be envisioned for patients. While the prevalence of direct pharmaceutical industry-to-patient relationships is currently unknown, they may be meaningful in introducing information to other patients, any lay audience, or clinical providers. To avoid potentially negative impacts of industry–patient relationships on clinical care, clearly articulated procedures should be developed and implemented to address financial inducements of patient advocates, most importantly requiring declaration of conflicts of interest. Furthermore, financial relationships contingent on receiving treatment should be prohibited.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Author contributions
Meredith A. Bryarly: Conceptualization; Data curation; Investigation; Validation; Writing – original draft.

Michael A. Rubin: Conceptualization; Data curation; Investigation; Validation; Writing – original draft.

Olaf Stuve: Conceptualization; Data curation; Investigation; Project administration; Supervision; Writing – original draft.

Acknowledgements
OS serves on the editorial board of Therapeutic Advances in Neurological Disorders. Therefore, the peer review process was managed by alternative members of the Board and the submitting editor was not involved in the decision-making process.

Funding
The authors received no financial support for the research, authorship, and/or publication of this article.

Competing interests
OS has served on data monitoring committees for Genentech-Roche, Pfizer, Novartis, and TG

Therapeutics without monetary compensation, has advised EMD Serono, Celgene, Genentech, Genzyme, TG Therapeutics, and VYNE, currently receives grant support from EMD Serono and Exalys, is a 2021 recipient of a Grant for Multiple Sclerosis Innovation (GMSI) by Merck KGaA, is funded by a Merit Review grant [federal award document number (FAIN) BX005664-01] from the US Department of Veterans Affairs, Biomedical Laboratory Research and Development, and is funded by RFA-2203-39314 (PI) and RFA-2203-39305 (co-PI) grants from the National Multiple Sclerosis Society (NMSS). OS is Associate Editor of Therapeutic Advances in Neurological Disorders; therefore, the peer review process was managed by alternative members of the Board and the submitting Editor was not involved in the decision-making process.

Availability of data and materials

Not applicable.

ORCID iDs

Michael A. Rubin https://orcid.org/0000-0002-3177-133X

Olaf Stuve https://orcid.org/0000-0002-0469-6872

References

1. Yang T and Wu Y. A study on the influence of patient participation on patient trust-based on sample survey in China. *Front Psychol* 2018; 9: 2189.
2. Buljac-Samardzic M, Clark MA, van Exel NJA, *et al*. Patients as team members: factors affecting involvement in treatment decisions from the perspective of patients with a chronic condition. *Health Expect* 2022; 25: 138–148.
3. Davis RE, Jacklin R, Sevdalis N, *et al*. Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expect* 2007; 10: 259–267.
4. Mansell D, Poses RM, Kazis L, *et al*. Clinical factors that influence patients' desire for participation in decisions about illness. *Arch Intern Med* 2000; 160: 2991–2996.
5. Muth CC. Conflict of interest in medicine. *JAMA* 2017; 317: 1812.