LETTERS TO THE EDITOR

Response to Lai et al., “Development of a Symptom Index for Patients with Primary Brain Tumors”

We read with great interest the article by Lai et al., “Development of a Symptom Index for Patients with Primary Brain Tumors” [1]. Although we agree on the importance of symptom assessment in patients with primary brain tumors, we would like to clarify several points in the article related to the MD Anderson Symptom Inventory for Brain Tumor (MDASI-BT):

1. We agree that incorporation of input from both patients and clinicians is critical for instrument development. The author suggests in the discussion that the MDASI-BT did not incorporate patient or clinician input and that it was not developed specifically for patients with advanced brain tumors.
   a. The MDASI-BT design and validation process did incorporate clinician, patient, and caregiver input about the symptoms included in the instrument, including review of suggested symptoms and allowance for suggestion of important items not initially included [2]. In addition, calculation of a content validity index was undertaken [3].
   b. An additional critique is the lack of validation of existing instruments in patients with advanced brain tumors. We might mention that the MDASI-BT validation work included patients with all grades of primary tumors and both patients who were on treatment and patients who had experienced recurrence [2]. Since the initial validation, additional work has shown the MDASI-BT’s sensitivity to tumor progression on magnetic resonance imaging [4], as well as its ability to predict both overall survival and progression-free survival and sensitivity to between-arm treatment differences, as evidenced in two of the largest randomized clinical trials among patients with brain tumor completed to date [5,6].

2. One of the article’s arguments for the need for a symptom index is that there are differences between the European Organization for Research and Treatment C30-BN20 and the MDASI-BT. These differences, however, are not unexpected because the former is a quality-of-life measure and the latter is a measure of symptom burden.

3. Lai et al. commented that the 0 to 10 rating scale does not distribute equally on a measurement continuum and should not be used to measure change over time. However, this claim was based on comparing a single pain item rated on a 0 to 10 scale against a six-item short form and an item bank with 43 items. There is no question that a single item will perform poorly in this comparison as far as measurement precision is concerned. Note, however, that this claim goes against the National Institutes of Health Toolbox (http://www.nimh.nih.gov/toolbox/index.shtml)’s recommendation use of a 0 to 10 scale to assess pain intensity [7] and is in contrast with the adoption of the 0 to 10 scale for rating pain in the 10-item global Patient-Reported Outcomes Measurement Information System assessment, in which pain is the only item measured using the 0 to 10 scale [8].

4. An additional critique centers on the recall time frame. The authors claim that a 7-day time frame may better represent the patient’s real experiences than the 24-hour time frame used by the MDASI-BT. We agree that this is an important question. We recently published our work in the brain tumor population comparing 7-day and 24-hour reports, with this initial study showing congruence between the two time frames [9]. This same article showed desirable psychometric properties for the MDASI-BT with a 7-day recall.

5. Finally, most of the final items included in the National Comprehensive Cancer Network/Functional Assessment of Cancer Therapy-Brain Symptom Index (NFbrSI-24) are included in the MDASI-BT as well. Some items identified (such as headaches and fear of having seizures) were considered in the initial validation study of the MDASI-BT and were found to be redundant with items that were eventually retained; other items were consistently rated by patients as less severe and proved to be less discriminatory, and therefore were removed from the final MDASI-BT. Several items in the NFbrSI do not truly represent symptoms and their inclusion on a symptom measure is a matter of debate.

In summary, we believe that the NFbrSI may be a useful tool under appropriate circumstances. Even so, we appreciate the opportunity to provide clarification regarding the development and use of the MDASI-BT.

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1098-3015/$36.00 – see front matter Copyright © 2014, International Society for Pharmacoeconomics and Outcomes Research (ISPOR). Published by Elsevier Inc.
http://dx.doi.org/10.1016/j.jval.2014.06.004

Source of financial support: The authors have no other financial relationships to disclose.
REFERENCES
