Patients are the best judges

Evaluating quality of life in CNS tumor care

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Health-related quality of life (hrQOL) is an often-neglected aspect of care in neurologic disease,¹ and all the more so in the management of CNS cancers.² Knowledge about pathologic grade, extent of tumor burden, and anatomic location may provide little comfort for patients who are coping with diagnoses that cause anxiety, pain, sleep problems, and social isolation. Physician-reported outcomes may focus on physical health with less ability to discern psychosocial dysfunction resulting from the condition. In contrast, patient reported outcomes (PROs) measure quality of life in domains that matter most to patients.

In this issue of *Neurology® Clinical Practice*, Chaitoff et al.³ demonstrates an attempt to implement a well-known PRO instrument in a patient population with nervous system tumors. The NIH-developed Patient Reported Outcomes Measurement Information System (PROMIS) questionnaire was administered to patients with gliomas of all grades, CNS lymphoma, meningiomas, as well as pituitary tumors, schwannomas, and CNS metastases. PROMIS evaluates hrQOL in 6 domains, including pain, fatigue, and social satisfaction. The results were compared to 2 single item physician reported outcome scales that have been previously validated in brain tumors, the Eastern Cooperative Oncology Group (ECOG) performance scale, and the Karnofsky Performance Scale (KPS). While the ECOG and KPS scores demonstrated strong statistical correlations with each other, correlations with PROMIS were only weak or moderate in this patient population.

The findings suggest a gap between physician- and patient-reported QOL metrics. Both KPS and ECOG provide an ordinal scale score corresponding to function secondary to severity of illness as determined by the physician: 0–100 for KPS,⁴ and 5–0 for ECOG.⁵ As both scales are taken from the physician perspective and provide general ratings of disability and health, it is unsurprising that this study reprises the conclusions of prior analyses showing these are correlated.⁶ But physical health and ability to perform self-care may not encompass all important facets of patient quality of life. In contrast, the multiple domains of PROMIS capture aspects of patient health not seen on physician assessment metrics of physical function.⁷

The study has multiple limitations. The population is a convenience sample of persons seen for neuro-oncological care at a single tertiary referral care center with a heterogeneous grouping of conditions, including “benign” and rapidly progressive conditions with a variety of prognostic implications. The results were not adjusted for age, comorbidities, treatment adverse effects, or functional anatomical involvement. The size of the sample is substantial, but subgroups based on tumor type or staging are considerably smaller. As expected, the glioblastoma and metastatic tumor patients had a higher symptom burden than the rest of the studied population. Given the effect of cognitive and language problems, caregivers were allowed to report as proxies for these patients. Therefore, reported findings may not be generalizable or specific to pathology. Multiple readings on the same patients were not done, so measures of intrarater reliability have not been established. Lastly, there was no comparison with another PRO scale, such as Short Form-36 (SF-36) or EuroQOL-5D (EQ5D), so the performance of PROMIS relative to other PROs in this patient population was not established.

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Despite these issues, this study represents an important effort in exploring quality of life among patients where success or failure is often defined merely as survival. Further steps would include repeated PRO measurement with disease progression and throughout the course of available therapeutic interventions. PROs are a valuable source of health utilities for economic analysis, and the conversion of PROMIS scores to utilities allows for determination of quality-adjusted life years for decision analysis among competing therapies combining outcomes of both cost and effectiveness.⁸ As more studies involve PROs in this population, we will likely see a greater voice for patients in guiding critical decision-making and care.

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