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New federal rule requires open notes: what do clinicians and patients need to know? Insights and suggestions from a neuro-oncologist, a neurosurgeon, and a person living with a brain tumor

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Starting April 5, 2021, a new US federal rule will be implemented as part of the 21st Century Cures Act that in part mandates patients will be able to access their test results, medication lists, referral information, and clinical notes rapidly and conveniently in electronic formats… "without delay."[1] As a result, it will be easier for patients to access the information in their records, including progress notes. As of December 2020, more than 260 health care institutions in all 50 states have offered access to clinical notes ("open notes") through online patient portals[2]; however, access to this information has not been uniformly applied across the country despite existing functionality within electronic health records. In the practice of neuro-oncology, this kind of transparency and immediate access to information may represent a culture change for health care providers, patients, and their caregivers.

Clinicians, patients, and caregivers have all weighed in on their experiences with open notes. In multiple studies, clinicians agree sharing progress notes is helpful for engaging patients and would recommend the practice to colleagues.[3] Patients report benefits from reading these notes as doing so helps them remember care plans, adhere to their medication regimens, share accurate information with caregivers, and feel more in control of their care.[4,5] Caregivers report better assisting patients with medications, as well as more trust and better teamwork with clinicians.[6]

Sharing progress notes with patients in oncology is not new: MD Anderson Cancer Center began the practice in 2009 and reported similar benefits,[7] however, there have only been a handful of studies of open visit notes in oncology settings. In a recent multicenter survey, both oncology clinicians (70% of 96) and cancer patients (98% of 3418) agreed open notes was a "good idea." However, 44% of oncology clinicians believed reading notes would be confusing for patients, though just 4% of cancer patients reported feeling confused. Additionally, while just 28% of oncology clinicians believed patients would find the notes helpful, 56% of cancer patients considered notes important in preparing for medical visits.[8] Oncology clinicians may be underestimating their patients' capacity to understand the content of visit notes.

Any change in practice has both perceived and real challenges worthy of exploration. For example, patients who view their records may find inaccuracies and request that changes be made. In one survey, about 1 in 5 patient respondents reported finding a mistake in their visit notes, with many (40% of 4830) describing at least one mistake as serious.[9] To reduce the burden on physicians of responding to change requests some organizations have designed new processes for patients to report inaccuracies; in one study of such processes, physicians reported no negative impact on workflow or patient relationships.[10] Some may also worry about litigation from patients who read their records. We know of no malpractice claims filed as a result of shared visit notes, and data related to other forms of transparent communication in health care suggest open communication about errors may not increase claims or liability costs.[11] While most clinicians say they did not change their documentation after switching to open notes, some have reported changing how they document sensitive topics such as obesity, sexual history, or mental health, or language that could be perceived as critical of the patient.[3,12] Changes in documentation with open notes is an area that warrants more research, especially as it relates to the suspicion of cancer, life-threatening diagnoses, and prognosis.

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After 5 years of collective experience with open notes (and conversations with clinicians across the country), Klein and colleagues at Harborview Medical Center suggested clinical documentation may be optimized for patient readers by using supportive language ("the patient chose not to pursue treatment," rather than "the patient refused treatment"), and by being familiar with how to amend notes ("thanks for pointing out that I wrote 'right knee' rather than 'left knee'; I'll be sure to note the correction in your chart"). They also suggest clinicians be prepared for the rare instance when a patient disagrees ("I'm sorry you disagree with my assessment that alcohol contributed to your fall. While I can't change my medical opinion, if you'd like I can add that you disagree with it").[13]

We know of no specific guidance nor formal study for neuro-oncologists and neurosurgeons on open notes, and there has been no formal study of brain tumor patients' perceptions. Of 35 US institutions offering accredited neuro-oncology fellowships through the United Council of Neurologic Subspecialties,[14] 26 report the capability of sharing notes with at least some patients,[2] though the method of note sharing is unclear. For now, the authors offer suggestions for information that both neuro-oncology clinicians and patients want at their fingertips (Table 1), as well as personal reflections on sharing and reading visit notes (see panel at the end of this text).

Neuro-oncology is a highly specialized and rapidly evolving field, with many potential communication challenges. When patients and clinicians are on the same page, looking at the same information, a patient's level of understanding increases. Now that the US health care system mandates patients have immediate access to information in their records with no delay, we will need to think about what this means for those who choose to view this information, *and* for those who would prefer not to. This may be a good opportunity to help forge more effective clinician-patient partnerships by putting neuro-oncology patients squarely in the center of their own care.

Table 1. Suggested Documentation Adjustments to Help Patients Benefit From Reading Their Neuro-Oncology Notes

Suggestion	Examples
Consider a standard template which allows others to quickly find pertinent information	Include neuro-oncology care team: • *Neuro-oncologist: Dr. X* • *Neurosurgeon: Dr. Y* • *Radiation-Oncologist: Dr. Z* • *Palliative care: Dr. A* • *Advanced Practice Provider (PA-C/ARNP): Joe Smith, NP* Include neuro-oncology treatment summary: • *August 22, 2017: Right frontoparietal craniotomy for excision of glioblastoma, IDH wild type. Dr. Y* • *September 18, 2017-October 27, 2017: Proton therapy with concurrent Temozolomide, Dr. Z* • *December 14, 2017-January 26, 2018—Bevacizumab 10 mg/kg* • *December 1, 2017-March 22, 2018: Completed 4 cycles of TMZ then discontinued due to MGMT unmethylated and very poor tolerance with profound fatigue and cytopenias* • *April 2, 2020: Definite radiographic tumor progression* • *April 20, 2020: Gamma Knife* • *May 1, 2020: C1D1: CCNU* • *June 13, 2020: C2 CCNU* • *July 27, 2020: C3 CCNU* • *INCLUDE: PERSONAL REVIEW OF RADIOGRAPHIC RECORDS to allow subsequent discussion of your interpretation of brain MRI changes in the context of treatment, which may not be captured in the official reading by the neuroradiologist and are a frequent source of questions by patients and families*
Write a complete social history	Social history may include: • Names and ages of children and pets • Occupation • Place of residence, and who lives in the home • Other important aspects of a patient's life • *"He has 1,100-1,200 people following his CaringBridge site"*
Stress positive prognostic indicators, if possible	• Indicators may include: MGMT methylation, IDH mutation, the absence of enhancement, etc. • If there are only negative prognostic indicators, try and discuss them in context. *"We discussed all the prognostic indicators in the visit and concluded that given age over 70 and the absence of MGMT methylation that the benefits of chemotherapy would not outweigh the risks"*
Add a "Summary for patient" section	Create a "Summary for Patient" section to convey information most relevant to patients. This may repeat the "Plan" section of the note and/or include relevant resources from brain tumor organizations

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Personal Experience With Sharing and Reading Neuro-Oncology Notes

NEURO-ONCOLOGIST EXPERIENCE: Lynne P. Taylor, MD

I have been working in an open notes environment for many years but recently have focused more on the emotional content of my notes for my patients rather than a document to share medical decision making with my colleagues. One recent experience sticks in my mind. I am treating a young man with a glioblastoma whose tumor is growing rapidly, unfortunately. He recently asked me why I had used the word "futile" in my description of my care plan as he did not think that it reflected the discussion that we had in the clinic. While I was surprised to find that I had used that word, his honest questioning led us to a very productive discussion about his goals of care and the likelihood of the current therapy improving his quality of life.

NEUROSURGEON EXPERIENCE: S. Alireza Mansouri, MD

As a neurosurgeon I see people with brain tumors at very stressful times, often when there has been a first ever diagnosis of a lesion. Herein, it is critical to prepare patients and their care partners as much as possible for what to expect leading up to and beyond the period of surgery. The open notes environment has served as a wonderful opportunity for officially documenting this information. Including a section titled "Summary for Patient" has been helpful in conveying relevant information to my patient, along with resources in the brain tumor community, while separating it from medical jargon.

PATIENT EXPERIENCE: Liz Salmi, recurrent low-grade glioma

There's a lot coming at you right after a brain tumor diagnosis. Reading my neuro-oncology notes helps me remember what my doctor and I talked about. The notes include words I don't know, but I'm able to figure out what it all means from context, because it was about my visit. Today my scans and visits are spaced 12 months apart and it's easy to forget what happened from the previous year. It would have been helpful to have access to this information sooner in my diagnosis. For every question I have, or thing I forget, it's all there in the notes.

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Editorial statement. This text is the sole product of the authors and should not be interpreted as technical or legal advice. Consult with your organization's health information management, compliance, legal, finance, and public affairs teams to find out how the 21st Century Cures Act Final Rule on Interoperability, Information Blocking, and the ONC Health IT Certification Program applies to you.

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