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# Practical guidance for telemedicine use in neuro-oncology

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#### **Abstract**

While the COVID-19 pandemic has catalyzed the expansion of telemedicine into nearly every specialty of medicine, few articles have summarized current practices and recommendations for integrating virtual care in the practice of neuro-oncology. This article identifies current telemedicine practice, provides practical guidance for conducting telemedicine visits, and generates recommendations for integrating virtual care into neuro-oncology practice. Practical aspects of telemedicine are summarized including when to use and not use telemedicine, how to conduct a virtual visit, who to include in the virtual encounter, unique aspects of telehealth in neuro-oncology, and emerging innovations.

#### Keywords

telemedicine | telehealth | neurological examination | clinical trials | caregiver

Telemedicine is defined as the use of electronic information and communication technologies to provide healthcare when patients and providers are separated by distance.<sup>1</sup> Telemedicine has been utilized in neurologic care since the early 2000's when stroke centers expanded access to acute stroke interventions through telestroke networks.<sup>2–4</sup> Since that time, telemedicine has expanded modestly, primarily to address barriers to access and increase subspecialty care in

rural or underserved areas.<sup>5–7</sup>The COVID-19 pandemic in 2020 catalyzed rapid expansion of telehealth across the globe. Providers, health systems, and insurance companies extended coverage to accommodate physical distancing, limit patient-provider exposure, reduce hospital resource burdens, maintain continuity of care, and limit the spread of the virus.<sup>8</sup>

In the wake of these structural reorganizations and public health safety pressures, telemedicine services were implemented broadly throughout neurology and oncology.<sup>9-11</sup> In oncology, telemedicine has been used to improve access to care for rare cancers,<sup>12</sup> facilitate interdisciplinary care,<sup>13</sup> and augment palliative oncology,<sup>14</sup> and was expanded during the COVID-19 pandemic.<sup>12</sup> Telemedicine has also been feasible in front-line neurologic care,<sup>15</sup> epilepsy,<sup>16-18</sup> pediatric neurology,<sup>19</sup> headache medicine,<sup>20</sup> multiple sclerosis,<sup>21-23</sup> neuromuscular medicine,<sup>24,25</sup> neuro-ophthalmology,<sup>26,27</sup> and neuro-palliative care.<sup>28</sup> Recognizing the importance of telehealth in future practice, telemedicine has been adopted in training programs.<sup>29-31</sup>

Despite the substantial attention to telemedicine in neurology and oncology, significant gaps remain, particularly in neuro-oncology. A 2020 review by the telemedicine working group of the American Academy of Neurology (AAN), summarized the evidence-based benefits of telemedicine including expediting care, increasing access, reducing cost, improving diagnostic accuracy, and enhancing outcomes. The report highlighted studies that demonstrated noninferiority between telemedicine and in-person visits in terms of patient and caregiver satisfaction. Notably, of the subspecialties discussed, no studies were specific to neuro-oncology.

In order to identify current telehealth practices and generate guidance for telemedicine in neuro-oncology, a telemedicine working group of adult and pediatric neuro-oncologists was formed. Interested members were solicited from the Neuro-Oncology Section of the American Academy of Neurology and a working group formed to discuss telemedicine practices, identify common barriers and solutions, and generate practical guidance. The group met regularly over the course of 6 months. Each section was reviewed by all members of the working group, which included adult and pediatric providers. Identified differences were resolved, when possible, to recommend a common approach. Alternative practices were also acknowledged in the text.

This article provides practical guidance for neuro-oncologists on how to integrate telemedicine into their practice including when to consider a telemedicine encounter, who to include in the visit, successful strategies for conducting telemedicine in neuro-oncology, and emerging innovations (e.g., multidisciplinary virtual visits, advance care planning). The article highlights areas where neuro-oncology serves as a model for how telemedicine can be leveraged in other specialty areas including virtual treatment and clinical trial consent, delivering difficult news related to prognosis and end-of-life, virtual tumor boards, and improving geographic access to clinical trials.

# Section 1: When to Use or Not Use Telehealth in Neuro-Oncology

Opportunities to Enhance Neuro-Oncology Care via Telemedicine

Neuro-oncology is a small subspecialty with fewer than 300 board-certified neuro-oncologists practicing in the United States. It is common for patients to travel long distances to see a specialist. Prior studies in oncology have

shown that increased travel requirements are associated with more advanced disease at diagnosis, inappropriate treatment, worse overall prognosis, and a worse quality of life.33-36 For patients and caregivers, major benefits of telemedicine include decreased travel time and expense, decreased physical and emotional burdens, increased satisfaction, and increased access to subspecialty care and clinical trials.<sup>37</sup> Patients with primary and metastatic nervous system tumors often suffer significant neurological and functional impairments. As symptom burden increases with disease progression and symptoms are more dynamic, traveling outside of the home can be challenging for patients and caregivers at a time when it is most difficult and important. In such cases, telemedicine visits allow for shorter, more frequent, remote check-ins, which optimizes symptom management.

For providers, telemedicine visits allow for flexibility in scheduling patients even at times that were previously considered "nonclinical" hours. Neuro-oncologists, like other providers, traditionally provide many hours of care to patients without reimbursement: time spent managing symptoms on the telephone, explaining laboratory results, reviewing imaging studies, titrating medications, educating on chemotherapy side effects, coordinating with social workers, and talking with caregivers. Increasing the frequency and availability of telemedicine visits enhances access to the provider while also remunerating them for the provision of clinical services.

Telemedicine visits require preparedness for the provider, the clinical practice, the patient, and in many cases also the caregiver. This can result in additional burden on all fronts. Selecting the appropriate visit indications and procedures to help minimize this burden is important.

#### Encounters Most Suitable for Telemedicine

Some visit types may be well suitable for telemedicine such as chemotherapy monitoring visits, chemotherapy consent, and education, discussion of new laboratory or imaging results, and provision of a second opinion (Table 1).

Chemotherapy monitoring.—In addition to intravenous chemotherapy regimens, neuro-oncology patients often receive oral chemotherapy (e.g., temozolomide for patients with glioblastoma). Patients on treatment require regular follow-up visits and monitoring of blood work to monitor for symptom burden and side effects from therapy. Virtual visits provide patients with a provider assessment in between in-person visits and allow for reporting of symptoms at frequent intervals. Regular patient-provider symptom assessment improves communication.<sup>38</sup> These visits also create opportunity to review medication compliance and discuss results of blood work performed for chemotherapy monitoring.

Treatment consent & education.—Treatment consent is fundamental to neuro-oncology practice and part of the neuro-oncology quality measurement set.<sup>39</sup> Consent for treatment often occurs at times that are overwhelming for

Table 1. Practical Considerations During a Telemedicine Encounter in Neuro-Oncology		
Aspects of neuro-oncology care considered suitable for telemedicine	Aspects of neuro-oncology and general medical care that may represents a barrier to telemedicine	
Remote monitoring of select chemotherapy regimen, e.g., oral chemotherapy	Conduct of neurological and physical examination	
2. Treatment consent, education, and counseling	2. System and user technical challenges	
3. Remote surveillance visits	3. Insurance reimbursement	
4. Urgent symptom evaluation	<ol> <li>Patient-centered communication: not ideal for difficult discussions (e.g., at the time of disease progression, end of-life care, and transition to hospice)</li> </ol>	
<ol><li>Monitoring of patients using tumor-treating fields (skin toxicity, compliance)</li></ol>	<ol><li>Altered dynamics and requirements of the caregiver: while they may be needed, the focus of the encounter must remain on the patient</li></ol>	
6. Second opinion and clinical trial eligibility evaluation	<ol> <li>Additional workload on neuro-oncology provider and clinic staff; potential for provider burnout if telemed- icine visits cut into time typically reserved for other responsibilities</li> </ol>	
7. Other education and counseling that is beyond the scope of a patient- portal or phone exchange (documentation, billing, ordering, routing)	<ul> <li>7. Not ideal for discussions at the time of progression and transition to hospice, nor monitoring of more complex treatment regimens and clinical trials</li> </ul>	

patients and caregivers including at the time of initial diagnosis, disease progression, or treatment changes. There is a lot of information to cover in these visits. Providers review the diagnosis or stage of treatment, pathology reports, imaging results, prognosis, goals of care, treatment option(s), and the benefits and risks. Retention of information by patients at these visits is often poor. When a therapeutic plan is selected, completion of the consent, treatment education, and counseling can be difficult to remember for patients and caregivers who are also processing bad news. A follow-up virtual visit allows for a more thorough review of treatment indications, risks, benefits, administration, and schedule. This can enhance patient/provider understanding and allow sufficient time for questions.

Remote surveillance visits.—It is common for patients to be seen every 2-3 months during treatment, typically at the time of surveillance imaging. Patients who prefer to have imaging performed locally may benefit from virtual surveillance visits. Telehealth technology allows for screen-sharing to facilitate review of imaging with patients remotely. For patients with stable symptoms and imaging, remote evaluation can avoid travel-associated burdens and still meets patient care needs.

Urgent symptom evaluation.—New acute and subacute symptoms commonly arise in brain tumor patients. Some of these symptoms require rapid evaluation in person and others may be addressed with medication adjustments at home. In-person urgent evaluations contribute to considerable resource utilization and have prompted the development of urgent care oncology clinics to reduce Emergency Department utilization.<sup>41</sup> Urgent virtual visits have been implemented during the pandemic to evaluate initial symptoms and determine the need for in-person evaluation. In many cases, symptoms can be successfully

evaluated and managed virtually. If a more serious concern arises during these remote visits, in-person evaluation at an urgent/emergency care center may be warranted.

Second opinion encounters.—As in other oncology subspecialties, neuro-oncology patients frequently seek second opinions. These are often sought from providers who are geographically distant from the patient. Second opinions allow patients to receive general education on their condition, review treatment options, and recommendations, as well as be evaluated for eligibility in clinical trials. Telemedicine is well suited to provide these services without requirement prolonged travel and expense.

#### Challenges of Telemedicine

While telemedicine has been widely and rapidly adopted, important challenges will need to be overcome to integrate telemedicine into everyday neuro-oncology practice.

Challenges in conducting neurological/physical examination.—Even with high functioning patients assessed by video visit, providers rely on assistance from caregivers and family members in order to assess individual muscle group strength, visual symptoms, and others aspects of the neurological examination. Nuances of the examination may be difficult to assess by video (see Section #2). To date, wearable devices (e.g., smartwatches, biosensors, etc.) which may aid the virtual clinical assessment have not been integrated into widespread practice.

Communication challenges.—In general, video visits are preferable to telephone-only visits as they offer enhanced observation, communication and have been shown to be

cost-effective.<sup>42</sup> Recognition of subtle body language cues and emotions for the patient and provider can be difficult even with video. This may complicate provision of truly empathic care, especially for discussions around new brain tumor diagnosis, progression of disease, end-of-life, and goals of care. Studies show that patient-centeredness can be achieved virtually and is facilitated by strong pre-existing patient-provider relationships.<sup>43,44</sup>

Technical challenges.-Technical challenges have arisen with the expansion of telehealth services and resources during the COVID-19 pandemic. These can be divided into connectivity issues (e.g., broadband, Wi-Fi), device problems (e.g., computer, Smartphone), and user-related technical concerns. User-related challenges can be considerable in neuro-oncology particularly for patients with cognitive impairment and those with limited family or social support. This can also be difficult for non-English speaking patients and socioeconomically disadvantaged patients who do not have access to a computer or Smartphone. Provider support is often required to assist with connectivity malfunctions and user challenges such as when a patient's camera does not work. After an unsuccessful telemedicine appointment, patients may decline future telehealth evaluations, underscoring the importance of appropriately resourced clinical workflows.

Reimbursement challenges.—Insurance reimbursement is likely to drive postpandemic telemedicine practices. During the COVID-19 pandemic, Medicaid, Medicare, and most private insurers expanded telemedicine coverage considerably including both video and telephone-only visits. It is uncertain how coverage models will adapt postpandemic and to what degree telemedicine will be reimbursed. These decisions will be critical and are likely to impact practice patterns in neuro-oncology substantially.

Scheduling burden on the provider and practice.—It needs to be emphasized that telemedicine visits take as much if not more time than actual in-person visits. While the benefits have been clearly outlined above, the perception of telemedicine is oftentimes skewed and seen as an easier, time-saving alternative that requires less staff. In addition to technical challenges listed elsewhere, telemedicine encounters require staff support for medication review, depression screening, and practices that are considered standard for in-person visits to ensure that care does not suffer on account of the modality of the encounter.

### Integration of Telemedicine Into Neuro-Oncology Practice

Despite these limitations and challenges, there is broad consensus that telemedicine should remain part of neurooncology practice. Importantly, equitable integration of telehealth in neuro-oncology may require further resource investment, improving technical capabilities, and dedicated training to develop effective telehealth-communication skills. This may be particularly important internationally or in resource-limited settings where neuro-oncology patients may receive care from general oncologists, neuro-surgeons, radiation oncologists, or other providers. Prior studies have demonstrated significant geographic differences in neuro-oncology practice including palliative care utilization. Detimal integration of telemedicine will likely require local adaptations to meet the needs of patient and providers.

## Section 2—How to Conduct a Telehealth Visit in Neuro-Oncology

Telemedicine visits can be performed via telephone or by using a secure video conferencing platform. Individuals do not have to be co-located. Both telephone-only and video visits allow for multiple providers as well as the patient and one or more caregivers to join the visit.

#### Video Encounters

Video visits allow for direct patient observation, performance of the neurologic examination, review and sharing of imaging, and laboratory results, and simultaneous audiovisual communication between patient and provider. Video conferencing should utilize a video platform optimized for medical consultations rather than generic video conferencing software. Security and privacy are paramount. Prior studies indicate that videoconferencing is superior to telephone-only encounters with improved diagnostic accuracy and reduced hospital readmission. However, clear differences in access exist and may compound disparities with more widespread use of telemedicine. Regional differences and institutional support may impact the ease with which video visits are integrated into routine clinical care. 9,29,48,49

#### Telephone-Only Encounters

Telephone-only visits should be considered for patient encounters that require real-time two-way interaction when direct video observation is not needed. This may be considered for established patients with stable neurological symptoms and without the need to trend physical examination findings. Examples include long-term brain tumor survivors, patients not on active anticancer therapy, and patients with stable neurologic complications of cancer (e.g., chemotherapy induced peripheral neuropathy or tumor-related epilepsy). In addition to these scenarios, not all patients have video access. Prior studies have demonstrated barriers to video encounter for older, male patients with Medicare or Medicaid insurance.9 In such cases, the provider and patient, as opposed to payment policies, should determine the appropriateness of telephone-only or in-person visit, respectively.

#### Clinical and Practice Workflows

Training of clinical and administrative staff for telemedicine as well as patients is imperative. Administrative staff often take on the role of technology troubleshooting in addition to other clinical roles. Training and clarity of roles for the televisit are paramount to maintaining efficient clinical workflows. Patients need clear documentation and support to ensure that they have access to and are familiar with the technology and software. Caregivers may be required to assist patients when utilizing their device, particularly patients with cognitive or visual impairment (see Section 3: Patient-Caregiver Dyad). Adequate staff support and technical infrastructure is needed.

#### Special Circumstances—Patient Consent

Consent for treatment, clinical trial participation, genomic sequencing, or other procedures requiring informed consent are common in neuro-oncology. During the COVID-19 pandemic, provision of virtual consent in each of these circumstances was common. Postpandemic policies on virtual consent are likely going to be institution and encounter specific. We recommend that neuro-oncology practices have clear guidance on policies for virtual consent, proper documentation, and whether witnesses are recommended or required.

### Special Circumstances—Pediatric Neuro-Oncology

As with adults, telehealth use in pediatric neuro-oncology can provide increased access, promote continuity of care, improve quality of care, provide flexibility, and can maintain multidisciplinary involvement. It may frequently reduce child's stress and anxiety associated with in-person hospital or clinic visit. The pandemic has significantly impacted management of the childhood cancer patient, but has also helped to boost the popularity of pediatric telehealth, with parents more open to the idea of having their children attend virtual care visits. While some services provided to adult patients by telemedicine may not be easily adapted to or appropriate for pediatric patients given physical size, developmental state and age-specific differences in normal and disease states, multidisciplinary care is feasible. Telemedicine also provides access to the many subspecialty medical providers and psychosocial team, neuropsychology, and educational specialists needed for pediatric patients.

### Practical Tips for Conducting Telemedicine Encounters in Neuro-Oncology

If patients have the option of using more than one platform, administrative staff should clarify which platform is available and/or preferred. This should be clearly delineated in the chart so that providers are aware of whether they will log into the video platform, await notification from the Electronic Health Record (EHR), or notify the patient via a preferred method of contact.

- Imaging should be reviewed and shared with the patient when appropriate. Providers should ensure that
  the video platform has sufficient capabilities for screen
  sharing and that images are available.
- If a patient is in a facility or hospital, the primary caregiver, as well as a member of the staff at the facility, should be available. This should be arranged ahead of time.
- Patient should always be present during the telemedicine visit. It is not appropriate to have the telemedicine visit with family members or caregivers without the patient.

# Section 3—Who to Include in a Telemedicine Visit in Neuro-Oncology

In neuro-oncology, caregivers are as essential during both physical or telemedicine visits as they are for the communication and care they provide in between visits. Rapid implementation of telemedicine during the pandemic presented unique challenges and new opportunities to adapt the roles of the patient and caregiver dyad. Caregiver engagement in this dyad predicts prognosis in patients with glioblastoma and telemedicine has provided an opportunity to reduce burdens, increase inclusivity of the patient's broader caregiver team, enhance satisfaction, and improve outcomes.<sup>50</sup>

### The Dyad Perspective—Advantages and Disadvantages of Telemedicine

Virtual encounters have the potential to influence the patient-caregiver dyad both positively and negatively. Caregivers can be asked to take on the role of surrogate examiner or amateur videographer. Telemedicine has the potential to deputize caregivers who are no longer relegated to the sidelines and now function as the eyes, ears, and touch of the provider. For some, this can be a positive experience. The partnership can acknowledge the centrality of the caregiver role and enhance autonomy, validate self-efficacy, and strengthen the provider-caregiver relationship. For others, the need to assist in basic aspects of neurological examination is just one more duty.

In traditional in-person visits, providers rely on caregivers to provide or supplement the history, particularly as a patient's cognitive and/or language deficits progress. Virtual encounters may further task caregivers to assist with the provider-directed neurological exam. In doing so, caregivers may gain insight into work-around solutions or empowerment that can accompany understanding. Others may feel discouraged as they expose functions that a loved one has lost. Providers must be aware of this social and emotional impact of this new role as well as the impact it can have on the patient, caregiver, and their relationship. Providers should think critically about who is included in a telemedicine visit including the patient, primary caregiver, additional friends and family, and trainees (Table 2).

Table 2.   Attendance in the	Virtual Encounter—New Participants and New Roles
Mandatory participants	
Patient	<ul> <li>May be alone in some cases—i.e., good performance status, independent living</li> </ul>
Primary caregiver	Often lives with the patient
	Available for hands-on assistance
	<ul> <li>Commonly a spouse or adult child, but can also be sibling, parent, ex-spouse, close friend or othe relative</li> </ul>
	May be asked to hold camera or act as surrogate examiner
Provider	Physician provider
	Advanced practice provider
As needed participants	
Technical support	<ul> <li>If neither patient nor primary caregiver are able to connect due to disability or lack of technical skills</li> </ul>
Interpreter	Accessed by provider
Nursing staff	<ul> <li>If patient is hospitalized or in a rehabilitation facility</li> </ul>
	Often provide technical support
	<ul> <li>May be asked to hold camera or act as surrogate examiner</li> </ul>
Invited participants	
Relatives, friends	<ul> <li>Typically, their presence lends support to either the patient and/or primary caregiver dyad, but not always</li> </ul>
	<ul> <li>More likely to be present for more complex medical conversations—i.e., goals of care, clinical tria consideration, discussion of treatment options—rather than routine care</li> </ul>
Other providers	• Trainees
	<ul> <li>Consultants including but not limited to radiation oncology, neurosurgery, neuropsychology, pall ative care</li> </ul>
	Social work, nurse navigator, clinical trial coordinator
	Social work, nurse navigator, clinical trial coordinator

#### Patient

As with any clinical encounter, the patient is central to the virtual visit and should be present at any virtual encounter. In addition to the benefit of convenience, virtual visits can improve patient satisfaction by relieving caregivers of the hurdles needed to coordinate an in-person visit. With advancing disease, patients require increased support and resources. Consider the intense process of navigating between the home to the healthcare bedside, finding and paying for parking, safely transferring between vehicles and buildings, and burden of managing food/medicines away from home let alone managing toileting needs upon arrival. This relief of burden on caregivers can have a positive effect on patients.

Care must be taken not to sacrifice optimal communication for increased convenience. Methods of audio and visual communication should be optimized for the patient particularly for vulnerable populations. Similar to in-person visits, non-English speaking patients require interpreter services. Some telemedicine systems have direct connections to interpreters through the visit encounter, while in other circumstances a telephone or video conferencing third-party service is required. The presence of an interpreter on video may create an additional layer of complexity that influences the audio or video quality as well as patient communication. Policies and training are needed to guide providers on how to conduct a virtual visit with a non-English speaking patient utilizing an interpreter.

#### **Primary Caregiver**

As with in-person visits, it is valuable for a primary caregiver to be present for virtual visits. Convenience of telemedicine is not only a major advantage for patients but also for caregivers. In a survey conducted at Columbia University Irving Medical Center, patient-caregiver dyads routinely made reference to this. According to one, "[Telemedicine] is a more convenient way of speaking with the provider considering my mom is disabled. We are able to speak professionally and medically while being in the comfort of our own home. Also limits my mom from exposure to diseases" (Mary Welch, personal communication, June 10, 2021). Another wrote, "[telemedicine] was beneficial to be able to keep up with my doctor and not have to travel or arrange childcare." Many caregivers have additional demands on their time and availability. Some need to arrange for child or elder care; others simply cannot take a day from work or school without facing threats to job security, pay, or education. More than just convenience, telemedicine visits provide an opportunity to expand the caregiving team, add support for the caregiver, and streamline shared decision-making by also engaging additional friends and family.

#### Additional Friends and Family

By eliminating geographical barriers to visit participation, telemedicine offers patients a chance to include others

in conversations about their health, to involve them in medical decision-making. The potential advantages of increased inclusivity are obvious: relatives and friends who are unable to attend an in-person visit need not rely on second-hand information about diagnosis, prognosis, and treatment options. Through an internet portal, they hear the same information as the patient and primary caregiver in real-time, directly from the provider; they can ask for clarification, take notes for reference and advocate on the patient's behalf. This has the potential to cut down on misinformation, misunderstanding, and secondguessing that often adds to patient and caregiver burden. This also has the potential to cut down on the traditionally "nonreimbursed work" of electronic exchanges with caregivers outside of the visit. Moreover, when all interested parties are able to attend medical visits, primary caregivers can divest themselves of the task of keeping others updated and informed. Talking to families about a terminal diagnosis, tumor progression, or the end-of-life is never easy. With telemedicine, the task of delivering such news can remain with the provider.

Despite the advantages of increased inclusivity, participation by those outside the immediate dyad is not universally beneficial. In some cases, this can exacerbate an already challenging situation. Dysfunctional family dynamics can readily play out in a virtual environment, heightening the patient or primary caregiver's sense of social isolation and even placing the provider in the unwelcomed role of mediator. Expectation setting is essential. Similarly, technical issues with nonessential participants should not interfere with the scheduled visit.

### Special Populations—Who Should Attend a Pediatric Virtual Visit

A parent or legal representative should attend each pediatric virtual visit, in order to provide legal consent to participate. In addition, the presence of a responsible adult/ family member is even more crucial for the child or adolescent with a brain tumor in the same way that it is needed for the adult patient—in order to communicate with the treating team and provide a medical history and updates. The age at which a person may consent to care can vary with the health condition at issue, state of residence, or state where the patient is at the time of the telemedicine visit. If a parent is present, either in-person or remotely, there should also be provisions in place to have the parent/ legal representatives leave the room during confidential parts of the history and examination.

#### Special Populations—Trainees

Along with additional members of the patient's care team, telemedicine provides an opportunity to expand opportunities to experience brain tumor patients, learn telemedicine, and train in neuro-oncology. Given the unique differences in performing the physical and neurological examination, monitoring for chemotherapy toxicity, engaging in shared-decision making with patients, and communicating with caregivers, trainees should be actively involved in

telemedicine visits. Existing platforms allow for multiple providers to log onto the same visit including shared visits. Providers should familiarize themselves with the technology and workflow prior to the visit. For example, some providers will share a screen with trainees with co-located and others will use remote notification when separated.

#### Practical Tips for Enlisting Caregiver Support

- Technical requirements and limitations should be identified prior to the visit and strategies employed to mitigate. Previsit equipment checks and "practice runs" may be needed by staff. Live/archived tutorials on healthcare exchange platforms may be provided by the facility. If a patient is severely disabled, there should be someone who can operate the camera or assist with technical challenges.
- Providers should begin each virtual encounter by introducing themselves, making sure they are heard and seen, surveying who is present, who needs to be present, that the patient consents to the visit, and whether there are technical needs that should be addressed prior to conducting the encounter.
- Caregivers and family members may be invited to join virtual encounters and participate in shared-clinical decisions when appropriate and agreed upon by the patient.
- Medical interpreters should be used rather than family members. Ideally, the provider will contact the interpreter immediately prior to logging on so that they can assist with necessary introductions from the outset of the visit.

#### Practical Tips for the Provider Faced With Multiple Family Members

- Patients and their primary caregivers should be encouraged to invite others to the appointment, but with discernment. Patients, caregivers, and family members should be encouraged to speak to one another beforehand to ensure that they have the necessary equipment, login information and to confirm the time.
- In cases where the patient is physically unable to participate in the telemedicine visit, arrangements can be made to schedule a virtual family meeting instead.
- In advance, it should be made clear that visits cannot run overtime and the visit cannot simply transition into a lengthy patient-portal exchange. Instead, subsequent appointment(s) can be scheduled.

#### Section 4—Unique Aspects of Telemedicine Encounter in Neuro-Oncology

A critical component of the neuro-oncologic consultation is the neurological examination. While telemedicine has previously been used by stroke subspecialists to evaluate patients and improve the timing of administering thrombolytic therapy, prior to the COVID-19 pandemic it was unlikely for a neuro-oncologist to be trained to perform a neurological examination by telemedicine.<sup>51,52</sup> Few aspects of the neurological exam are unable to be performed or are limited by a video format (Table 3). Effort can be made to perform as much of the exam as possible.<sup>53</sup>

#### Practical Tips for the Virtual Neurologic and Systemic Examination in Neuro-Oncology

In general, the examination should be prioritized at the beginning of a video encounter in case video capabilities are lost during the evaluation. As with any virtual encounter, the provider should ensure that both patient and provider are in a well-lit room, able to be seen, and when able the video conferencing device (i.e., computer screen, smartphone, etc) should be stable on a flat surface and not held in hand. A list of medications or home vital signs is also beneficial. Because many neuro-oncology patients have cognitive or physical disabilities, it may be necessary for a caregiver or family member to be present as surrogate examiner.

#### Vital Signs

Vitals can be obtained with the help of a surrogate examiner (e.g., heart rate, blood pressure, respiratory rate) or if the patient is using smart devices (i.e., smartwatch) the readings could be taken from these devices directly (heart rate, blood oxygenation). Performance status can also be generally assessed here (KPS or ECOG).

#### General Appearance

Assessment of the patient's general appearance should be noted at the start of the exam. Providers should observe if the patient appears well-nourished, well-groomed, cachectic, or Cushingoid, and if they appear comfortable or in any pain. If the patient is following up from a postoperative procedure, then examination of the head for evidence of wound dehiscence should be performed. Providers should pay attention for signs of oral thrush that may be present.

#### Mental Status

The patient should be asked their name, date/month/year, and location to assess orientation. The patient may be

**Table 3.** Components of Neurological Exam Not Able to be Assessed in Routine Video Telemedicine Encounters

#### Smell (CN I)

Visual fields/acuity (CN II)

Fundoscopy

MuscleTone

Deep tendon reflexes (i.e., plantar responses)

Detailed sensory exam

Caption: CN, cranial nerve.

given a phrase to repeat and also shown objects (e.g., pen or badge) to name. Evaluation of the patient's responses should be used to evaluate for any fluency issues in their speech. Patients can be asked to touch their nose or close their eyes to examine if able to follow simple commands. Care should be taken to note signs of aphasia (i.e., receptive or expressive) or confusion.

#### **Cranial Nerves**

Eye movements may be evaluated by asking the patient to follow the examiners finger or to look in each direction. Reliable visual field exam may be challenging but can be attempted. Inspection of facial symmetry focusing on any decreased movement on one side of the face or flattening of the nasolabial fold should be performed. Hearing can be assessed by having the patient or surrogate perform finger rub at 6 inches from the ear. If the patient is able to hear the examiner via video platform and follow commands, hearing is typically well preserved. Shoulder shrug should be assessed for symmetry. Patients should be asked to open their mouth and be examined for soft palate movement and tongue deviation or atrophy.

#### Motor Examination

Patients should be asked to lift each limb individually (one at a time) up in the air to 30 °C for 5-10 seconds to assess if strength is at least antigravity. The examiner may observe for evidence of lower extremity edema at this time. Pronator drift and/or forearm roll can be assessed in the upper extremities. Finger tapping can be used to assess distal strength as well as coordination and motor modulation. The examiner can observe for tremors or abnormal movements. It should be noted that the examination of lower extremities may be challenging unless the patient is in bed and the camera can be positioned on the lower body by the caregiver. When asking patients to get up or move about the room, one has to make sure that the patient is safe to do so in order to avoid an accidental fall and potential injury (see below).

#### **Sensory Examination**

Sensory examination is best performed with the assistance of a surrogate examiner but can be performed by asking the patient to place a cool object on the top of the feet, hands, and face bilaterally. More detailed sensory discrimination typically requires a trained surrogate examiner (e.g., home health nurse).

#### Cerebellar

Patients should be asked to extend their arms outstretched in front of them, and then touch their nose with each index finger to look for signs of dysmetria (or use caregiver, parent). Dysdiadochokinesia can be assessed by asking the patient to tap the palm of one hand with the other hand and then rapidly turn over the fingers and tap the palm with the back of the hand. The patient's sitting posture should

also be noted. Presence of tremor could also be assessed during this part of exam.

#### Gait

Gait may be observable but will depend on the size of the patient's room, camera angle, and presence of caregiver or family member to observe or video. If a family member or caregiver is not available then walking, tandem gait, and Romberg testing should be deferred to avoid risk of a patient fall.

#### Skin

For patients undergoing tumor treating field (TTF) therapy inspection of the head is needed to look for any sign of skin irritation, infection, or breakdown.<sup>54,55</sup> Examination of the scalp should be performed in optimal lighting with the treatment arrays off. If arrays are present, patients may also be instructed to take a picture of their scalp when the arrays are changed and sent electronically for review.

#### Systemic Examination

For patients on active chemotherapy, a systemic examination is important to assess for signs of infection, lower extremity edema (i.e., that would suggest new deep venous thrombosis), bleeding or bruising, or other complications of treatment. Assistance from a caregiver or family member with positioning of the camera is important for assessing lower extremity edema or other more difficult to reach regions of the body.

### Special Populations—Practical Tips for the Pediatric Examination

Performance of the pediatric examination and neurologic assessment is tailored to the age and developmental stage of the child. General physical examination is essential for all patients and does not differ by age. In addition, for older children and adolescents, the approach to the neurologic examination is the same as in adults. For younger children, some preparation can be helpful, such as requesting in advance that there are age-appropriate toys and a flashlight available for the visit and asking the caregiver obtain a height, weight, and head circumference before the visit and to examine the skin for any lesions.

For the neurologic examination, much of the assessment is based on observation. Smell is typically deferred and deep tendon reflexes are impossible to assess, while the remainder of the examination is quite feasible with the aid of a parent/guardian/family member. Mental status tailored to the age of the patient can be assessed remotely. For visual fields, instruct the caregiver to hold a toy in front of the child and approach the peripheral vision from behind, assessing for shifting attention. A toy can be used to assess visual tracking and eye movements, while the flashlight is helpful to assess red reflex and palate. For motor examination of the younger child, start with observation in the caregiver's lap. Vertical suspension, stepping,

hyperextension can be assessed by video for infants. The provider can monitor crawling or gait and ask the child to get up off the floor from seated position or while lying flat on the ground. Reach for a toy or favorite object to assess for dysmetria. As with adults, more targeted motor and sensory assessments can be achieved with the help of the parent/guardian.

### Practical Tips for Difficult Conversations in the Virtual Encounter

Delivering bad news & end-of-life discussions.—Due to the poor prognosis of many nervous system malignancies, delivering bad news is an integral component of neurooncology practice. Difficult conversations are defined as a "report which deleteriously and profoundly affects an individual's outlook of his or her future." 56 Best-practices for how to engage patients and loved ones in these conversations virtually is entirely new to many neuro-oncologists. Few providers have received formal training. Templates such as the SPIKES protocol (Setting, Perception, Invitation, Knowledge, Empathy/Emotion, and Strategy/ Summarize) have been developed to assist with delivering bad news, but are challenging to implement virtually.<sup>57,58</sup> Recent adaptations have been proposed to improve their feasibility in the virtual context, but this remains an ongoing area of study.<sup>59,60</sup>

Providers should consider similar steps in challenging virtual conversations including (1) prepare the environment, (2) invite caregivers or family to be involved, (3) speak honestly and clearly, (4) connect with the patient and family, and (5) manage time constraints and interruptions.61 In the virtual environment, a quiet setting without distraction must be prepared for both the provider and the patient to avoid distraction or interruptions. 62 Telemedicine creates an opportunity to involve family members, significant others, or caregivers including those not physically present with the patient.<sup>59</sup> Prior to starting the visit, it is important to ask explicitly whether the patient approves of everyone present. Virtual communication limits some verbal and nonverbal cues. Studies show that patients and families have widely varying experiences with receiving bad news virtually with some families describing this as cold and impersonal.<sup>57</sup> The lack of physical contact (e.g., holding hands or hug) presents unique challenges for oncologists who utilize the laying on of hands to demonstrate empathy. Empathy is strongly correlated with health outcomes and further research and training are needed to determine how digital expressions of empathy can be achieved in neuro-oncology.<sup>63</sup>

### Practical tips for engaging the neuro-oncology care team through telehealth

Supportive care.—Treatment of brain tumor patients may require additional expertise in treating seizures, managing depression, providing emotional support and palliative care. Scheduling, coordinating, and attending numerous clinic visits can be challenging for patients with limited mobility and caregivers with work, family,

or other obligations. Virtual visits can enhance access to subspecialty-specific care in each of these areas without escalating financial, emotional, or psychosocial burden on patients and caregivers.

Virtual tumor boards.—Neuro-oncology is a multidisciplinary specialty that includes providers in neurosurgery, neuro-oncology, neuroradiology, radiation oncology, neuropathology, neuropsychology, neurology, and other subspecialty areas. 64-66 Interdisciplinary tumor boards allows for individual review of patient clinical status and imaging as well as providing input and recommendations from a multidisciplinary team of experts. During the COVID-19 pandemic, many neuro-oncology tumor boards to the virtual setting. This has permitted increased access to subspecialty providers who may have difficulty otherwise attending an in-person meeting as well as trainees and other learners. Neuroimaging, pathology slides, genomic analysis data as well as gross images from the operating suite can be presented and reviewed for clinical care and educational purposes.

# Section 5—Emerging Innovations in Telehealth in Neuro-Oncology

Telehealth in neuro-oncology presents new opportunities to explore models of patient care and to engage patients and caregivers in their medical care through multidisciplinary virtual visits, advance care planning, and enhanced clinical trial participation.

#### Multidisciplinary Virtual Visits

Multidisciplinary clinics are at the core of many neurooncology programs but these clinics can be difficult to build and sustain due to limited clinic space, scheduling conflicts amongst team members, and the growing geographic scope of medical centers.<sup>67</sup>

One opportunity is the ability for a patient to have a telehealth visit with their entire clinical team at once. Even when all specialties are represented in one clinic, a patient rarely sees all specialists at one time for a comprehensive discussion about their care. While clinics are multidisciplinary from the provider perspectives, clinic visits from the patient rarely fit this description. Instead, patients see clinicians sequentially in what patients often report as a long and exhausting day. Telehealth can break down some of these barriers<sup>68</sup> and are an opportunity to create visits where a neurosurgeon, neuro-oncologist, and radiation oncologist can have a comprehensive discussion with a patient in one single collaborative encounter.

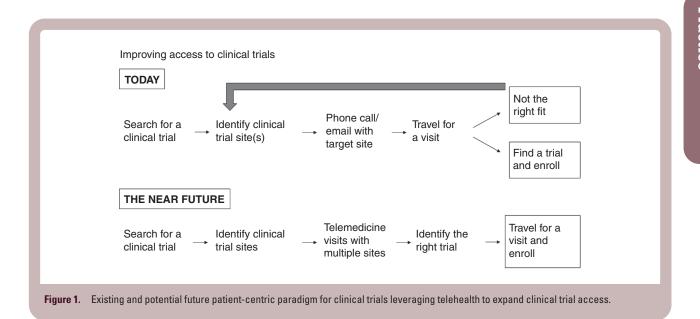
While multidisciplinary clinic visits may not be necessary or available for all neuro-oncology patients, it can be invaluable for patients with rare tumors, complicated treatment plans or treatments that stray from evidence. For example, at time of first recurrence in GBM, where there is

no consensus for treatment, a patient may get competing recommendations from team members including surgical therapies, radiation, or systemic therapies. A single, truly multispecialty, collaborative visit can be invaluable to a patient so they can hear from all team members at once, make a more informed decision-more efficiently, save time, save costs (multiple gas, parking fees, meals, childcare, lost work). Currently, each provider does need to perform the elements of a face-to-face encounter that justify billing, coding, and documentation and one would anticipate that as our medical care evolves, the logistics of billing will need to as well. Future billing models need to acknowledge the individual contributions from various providers in one single encounter. This type of visit can also be important for the complex care of patients with inherited tumor syndromes (e.g., neurofibromatosis, tuberous sclerosis), brain metastases, or neurologic complications of chemotherapy in systemic cancer patients that may necessitate dosing changes. In all cases, patients require input from numerous physicians who are not typically in a single clinic space at the same time.

#### Advance Care Planning & End of Life Care Visits

Several studies in advanced cancer have demonstrated the benefits of integrating supportive care in patient survival and quality of life. 69,70 For neuro-oncology patients this may include traditional supportive care services such as palliative care, mental health services, rehabilitation, and nutrition, or additional neurologic care focused on cognitive deterioration or tumor-related epilepsy. In most of these cases, an in-person physical or neurologic examination may not be critical. These services may not be widely available—especially with providers who have specific experience with neuro-oncology-and this may be an opportunity for brain tumor patients in the community to easily connect with tertiary care academic centers specifically for supportive care. Routine chemotherapy education visits may be difficult for community oncology providers who rarely take care of brain tumor patients, but these are crucial for clinical care and valued as a key quality measure.39

Advanced care planning is valuable but often difficult to include early in the disease course when visits are focused on initiation of therapy. In patients with brain tumors who may develop cognitive impairment, early discussion is critical to ensure that patients' values and wishes are respected at the end of life.71,72 Visits to discuss end of life goals require patient and caregiver education and family and caregiver involvement. Travel time and distance can be barriers, sometimes requiring family members to take additional time off from work.<sup>73</sup> Virtual visits reduce these barriers and have the added advantage of including distant family members and being done in the comfort of one's home. Some clinicians rightfully have concerns about discussing diagnosis and prognosis over a virtual platform and the effectiveness of such modalities will need to be further studied. Work in virtual palliative care has demonstrated that clinicians, patients, and caregivers are able to successfully navigate through these challenges.<sup>74</sup> Over the past year, we have individually integrated difficult conversations into a virtual format out of



necessity. Standardizing our approach to advance care planning may be more feasible with virtual options.

#### Inclusivity and Addressing Health Disparity

As academic medical centers work to bridge gaps with rural and underserved communities, access to resources needs to be an important part of that focus. A patient may receive anti-tumor care in the community, but can benefit from multidisciplinary input as well as brain tumor-specific supportive care resources. Provisions of these services virtually improves overall patient access.

#### Clinical Trials

Clinical trials are an integral component of neurooncologic care. Treatment guidelines recommend consideration of a clinical trial at the time of initial diagnosis<sup>75</sup> and recurrence.<sup>76</sup> The current process of finding the right clinical trial for individual patients is laborious, timesensitive, expensive and for many patients, requires travel. Patients are required to have an in-person visit to be assessed for eligibility on a clinical trial. If eligible, the patient will typically need further testing and visits before initiating the trial and then treatment-related and studyrelated visits for the duration of the study. Although the treatment and study-related care is financially covered by the clinical trial, travel and lodging expenses frequently are not. The current paradigm effectively excludes patients with financial limitations or inability to travel (Figure 1). At the same time, the neuro-oncology academic community and patient advocates recognize the critical importance of engaging more patients on clinical trials and improving access to emerging therapies.76,77 Virtual care needs to be a part of the discussion and has the potential to change the paradigm at every step of the process.

Virtual visits to determine participant eligibility from the provider perspective and the right fit from the patient perspective are feasible and empowers patients to more easily evaluate trials at multiple institutions. Trials should be designed to take advantage of virtual platforms whenever possible and in the future, should engage local oncologists in the necessary in-person visits. Clinical studies in Parkinson's disease have embraced wearable technologies to measure patient outcomes; in patients with brain tumors, these can serve as surrogates of fitness and quality of life. The changes needed here are significant and will require the efforts of clinical trialists, regulatory agencies, industry partners, and patient advocates in order to balance patient convenience with science and safety.

#### **Conclusions**

Prior to the COVID-19 pandemic, little data existed on the use of telemedicine in neuro-oncology practice. The care of patients with nervous system tumors requires that providers frequently perform the neurological examination, monitor for systemic toxicity, assess tumor response with imaging, and engage caregivers. Many neuro-oncology patients have significant neurologic impairments making it challenging for them and their caregivers to travel to see their providers in person. With the advances in telemedicine platforms, many issues frequently addressed during conventional office visits can be conducted via remote encounter including clinical trial enrollment, consenting, end of life care, and advanced planning—all integral to the practice of neuro-oncology.

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