Sharing notes with patients

A review of current practice and considerations for neurologists

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Abstract

Improved patient engagement is a critical consideration in the new payment climate. Releasing progress notes for patients to view may improve patient involvement and engagement in their care. Patients perceive benefit from viewing physician progress notes. As initial studies involved only primary care physicians, specialist physicians may have specific considerations when releasing notes to patients. This article provides a framework for neurologists to implement a note release policy in their practice.

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The concept of allowing patients open access to their medical record, specifically progress notes, gained steam in 2010 when a study funded by the Robert Wood Johnson Foundation began, called OpenNotes. More than 100 primary care physicians in 3 diverse institutions opened progress notes to patients for their review.¹ Twelve months later, 19,000 patients had received access to notes. Few patients reported feeling confused, worried, or offended, and most patients wished to continue receiving their notes. Patients reported feeling more in control of their care and more educated, and reported better adherence to their medications. Although up to 26% of physicians stated a preference not to continue with the pilot when surveyed, no physicians dropped out of the program once they could request to do so.²

Easier access to progress notes may increase opportunities for shared decision-making, patient engagement, and patients' ownership of their health. In addition, note release may improve patient satisfaction. Follow-up patient and provider surveys in the OpenNotes project revealed that 37% of patients reported feeling somewhat or much better about their doctor after reading their notes. Very few patients reported feeling somewhat or much worse about their provider. The majority of participating providers reported improved perception of patient trust and satisfaction.³ In addition, using a shared note to document rationale for all tests being ordered for a patient may enhance trust, understanding, and follow-up, and facilitate later explanation of test results.³ Providers may fear an increase in office phone calls with note release. However, fewer than 10% of patients reported contacting their physician office with questions regarding notes.³ While no specific government mandate exists for note release, release of notes could potentially improve provider scores in the patient electronic

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access and coordination of care through patient engagement/view, download, or transmit portions of the advancing care information objective of the Merit-Based Incentive Payment System proposed by Centers for Medicare and Medicaid Services.⁴

More than 10 million patients have access to clinician notes through patient portals or other means at multiple sites including many large health care systems.⁵ Although many of these sites began with release of primary care notes only, programs are rapidly expanding to all specialties, including neurology. Release of patient notes in a neurology office presents unique concerns. Neurologists often care for patients with severe, terminal conditions and psychiatric comorbidities; the documentation of these conditions, if not handled in a sensitive manner, could be upsetting to patients and families. This article will provide a framework for the practicing neurologist interested in note release to consider and implement an open notes policy in his or her practice.

General advice for medical notes

The primary purpose of neurologists' notes is to provide accurate and informative neurologic opinion and recommendations to referring providers and care teams for patient benefit.⁶ Although concern may exist that electronically sharing notes with patients may result in watered down notes, one should always write medical notes for their primary purpose while keeping in mind that they may be read by anyone with a right to access the chart, including patients, administrators, auditors, billers, lawyers, and researchers.

Checklists, templates, links pulling in data, or copy/paste functions can be used to make documentation more efficient. While these tools have been criticized for contributing to notes that stray from their primary clinical patient-centered purpose, increased transparency associated with shared notes may encourage improved documentation including "avoidance of pejorative language...and increased clarity in...care plans."⁶ Guidelines and reviews for specific conditions may offer neurology-specific recommendations on documentation but rarely on sharing this documentation with patients.

Documenting a sensitive history

Sensitive topics that arise during history gathering, including addiction or potential abuse, may concern neurologists when sharing notes with patients. Documentation should be accurate, objective, and nonjudgmental. A useful strategy is to use quotes to attribute information that is said by the patient (or others). Descriptions of patient's appearance and body language can be documented objectively. For example, rather than stating that a patient has alcoholism in the history, consider "patient states: 'I drink daily but I can stop anytime,'" or "has a history of alcohol dependency." Consider avoiding verbiage one would not state in front of the patient.⁷ For instance, instead of describing a patient as obese, one could qualify medically as "obese as based on elevated BMI" or simply "elevated BMI."

An editorial about mental health notes provides practical advice on documenting issues of abuse, neglect, and addiction.⁸ Suggestions include describing rather than labeling symptoms ("feels that people are out to get the patient" rather than "patient is delusional"), objectively documenting disagreements and challenges ("we agree to disagree on..."), and highlighting patient strengths rather than only documenting vulnerabilities to address when putting together a treatment plan.

Circumstances may exist where easy patient access to the note may pose potential harm (for example, an abusive spouse may be reading notes). In these cases, consultation with a risk management resource is advisable. Disclosure of the note release office policy to patients is helpful, in private if necessary. The patient may share whether there is risk for note sharing. In these cases, notes may be suppressed from release or delivered to the patient privately during the next clinic visit. The patient may also request records directly.

Documenting sensitive diagnoses (potential and actual)

Neurologists suspecting distressing diagnoses (e.g., neurodegenerative conditions or brain cancer) may be concerned that shared notes will produce unneeded anxiety or worry. One could write that a broad differential diagnosis is under consideration, including potentially serious diagnoses, which will be discussed in detail at follow-up visit after testing is complete. Diagnoses may be mentioned in ways that are clear to knowledgeable physicians but not specific enough to engender patient worry (i.e., chorea work-up includes evaluation for “genetic conditions” rather than “Huntington disease”).

Numerous reviews have covered strategies for communicating confirmed diagnoses that represent bad news for patients. For example, SPIKES (setting, perception, invitation, knowledge, empathy, strategy, summary) is a 6-step strategy first described for delivering oncology diagnoses,⁹ later applied to amyotrophic lateral sclerosis.¹⁰ Similar approaches can be used when handling situations where family asks not to disclose diagnoses to patients for fear of worsening worry, depression, or anxiety.¹¹

Issues of ambiguous or uncertain diagnoses also exist. For example, neurologists may make a diagnosis of a functional (psychosomatic, psychogenic, conversion) neurologic disorder based on inconsistency among reported symptoms, a normal elemental neurologic examination, and positive examination signs.¹² Most neurologists have developed their own approach to these patients, often tailored to the patient’s individual presentation. In addition to strategies described above,⁸ consistent documentation of diagnosis and plan is advised. If one uses the term “functional sensorimotor disorder” with the patient, then this term is what should be documented in the note. In movement disorders, the term “functional movement disorder” has been proposed as being more acceptable to patients while being a more scientifically accurate term than the more established “psychogenic movement disorder.”^{13,14} Frameworks on how to communicate these difficult diagnoses and management plans have been proposed¹² (see also neurosymptoms.org).

Documenting genetic testing and information

Issues of transparency vs confidentiality of genetic test results, heightened in settings of an electronic health record (EHR) and shared notes, have been articulately reviewed.¹⁵ Issues include access, privacy, confidentiality, decision support for physicians and patients, and effects on relatives. With regard to withholding genetic information from the EHR, Hazin et al.¹⁵ note that “neither the Health Information Portability and Accountability Act nor the Genetic Information Nondiscrimination Act have eliminated the risk of genetic discrimination—nor the fear of it—the interest in this practice (opting not to document in a medical record) is understandable,” with the observation that both “patients and providers using EHRs may prefer a nondocumentation approach to certain genetic test results under certain circumstances.”

Genetic information contained within a note should be accompanied by documentation that sufficient genetic counseling or interpretive information has been provided to the patient to understand the nature of the information present. As with any sensitive issue, the calculus of what to include or not include in a note (or even the medical record) will be individual and case-specific. Involvement with legal services, ethics committees, medical records, and compliance may be needed. Awareness of these issues along with objective, nonjudgmental, and accurate documentation of what actually is communicated to a patient during a clinic visit remains the most practical policy for practicing neurologists.

Prior to implementation, a practice should designate a responsible party to receive and address patient queries regarding shared notes and create a triage process.

Implementation considerations

Though not widespread, providers have shared notes even when this meant photocopying their charts or sending a dictated letter directly to the patient. This burdensome workflow has been streamlined through use of patient portals integrated into the EHR. While some EHR vendors have the capability to send notes directly to their patient portals, many smaller vendors may not yet support this functionality. The first step in implementation of shared notes is a discussion with the practice's vendor or IT team. Once it is established that this functionality is available, key implementation considerations include the remainder of the 5 Ws: who, what, when, and where (why having been addressed above). These decisions must be thoughtfully made as they will have considerable effect on adoption success (table).

"When" can apply to both an overall implementation strategy and to the specific timing of note sharing. Shared notes can be implemented across a health system/practice all at once or in a staggered fashion. Provider acceptance and readiness should factor into this decision. Notes should be shared from a specific implementation date moving forward. At the specific note level, the trigger for many EHRs to share the note is the closing of the visit encounter, as this prevents an incomplete note from being inadvertently released.

"Where" refers to the encounter setting. Currently many institutions are only sharing ambulatory notes; this initiative will likely soon spread to involve inpatient documentation as well.

In terms of "what" is shared, each note type should be individually evaluated for inclusion. A practice may decide to share consult and progress notes, but not documentation of telephone calls or procedures. How much autonomy each provider will have over the sharing of notes and at what level must also be decided. Some institutions allow for providers to opt out of participation in note sharing completely, while others allow them to opt in on individual notes of their choosing. In the latter scenario, nothing is shared by default; a provider

Table Decisions prior to implementation of shared notes

Method of implementation	Phased or Big Bang (all practices/providers at once) Opt out (notes shared by default) or opt in (notes not shared by default) Allowed overrides for opt out (allow suppression of some notes) or opt in (allow sharing of some notes) by encounter, provider, or practice
Which notes should be shared?	Ambulatory only, inpatient, or both Specific note type (history and physical and progress notes only vs inclusion of other notes types such as procedure notes and documentation of telephone calls)
When should notes be shared?	From date of implementation forward or include historical notes At close of encounter or once note is accepted
Whose notes should be included?	All providers/licensed independent providers (LIPs) only, or LIPs and select other roles How should trainee notes be handled?
How will patients be informed?	Options include large marketing campaign, signs in the office, letters sent to patients home or through portal, or conversations between patient and provider
Will proxy access be allowed to notes?	Proxy access allows for caregiver understanding (benefit of shared notes) but must be weighed against patient privacy concerns

may select individual notes to release. Alternatively, all notes of a certain type may be shared, with providers having to specifically decide to not share a particular note.

The “who” involves deciding which note author roles in the practice will be included, with consideration given to all providers and staff who author clinical documentation. In addition to licensed independent providers (LIPs) (physicians, nurse practitioners, and physician assistants), other roles that should be considered are trainees (medical students and residents¹⁶), nurses, social workers, psychologists, and therapists. The method of sharing may differ depending on the role. For example, all notes may be shared by default except those authored by a social worker or psychologist. It must also be decided who will have access to a patient’s notes. While proxy access to shared notes may improve caregiver understanding (especially for patients with cognitive impairment), privacy concerns exist.¹⁷

Additional considerations include the methodology and extent of provider and patient education and reminders and the timing of these in regards to implementation. Patient viewing of available notes may drop considerably without continued reminders.¹⁸ Prior to implementation, a practice should designate a responsible party to receive and address patient queries regarding shared notes and create a triage process. Options include use of a nursing pool followed by distribution of messages to LIPs as needed or vice versa. Although evidence thus far has not shown a great increase in patient calls following the implementation of shared notes,³ anecdotally, providers’ experiences have varied. Practice effects may differ based on patient population and practice size and a practice should be prepared to receive an increased volume of communication. The note release toolkits on the American Academy of Neurology website¹⁹ and OpenNotes Initiative⁵ website contain helpful information on these and other implementation considerations.

Legal considerations

The primary regulation to consider in employing shared notes is the Health Insurance Portability and Accountability Act (HIPAA).²⁰ Although this federal statute governs the privacy protections and security safeguards of health information, state regulations must also be considered as they may be more restrictive, and both require full compliance. Each state maintains distinct regulations pertaining to a patient’s right to his or her medical records. Regulations vary minimally state to state and generally relate to timeliness or release and whether records must be made available in an electronic format. Both federal and state regulations allow patients, or parents/guardians if a patient is a minor, to access their medical records upon written request.

HIPAA does not preclude the release of records to patients via a secure portal. The full scope of the federal and state regulations should be reviewed and compliance maintained. The following provisions of HIPAA require careful attention in relation to open notes.

Notice of privacy practices (NPP) Patients should be provided the organization’s NPP at the first treatment, or as soon as practical in emergency situations. This can be provided in person, via mail, or through electronic means, with written acknowledgment by the patient of receipt. The organization’s availability and disclosure of records via a secure portal should be included in the NPP as well as any limiting factors in which information may be denied due to the potential for harm to the patient if such disclosure were made. Limiting factors include restrictions on mental health notes, certain diagnoses, alcohol/drug abuse, and others if required by state law.

Business associate/business associate contract The organization is to maintain a business associate contract with the EHR vendor and the portal vendor, if not the same company. This is required since the vendors provide services that involve the use of protected health information (PHI) and are subject to all the same privacy and security regulations.

Personal representatives/minors A personal representative, generally the parent of a minor, maintains the same rights as relates to uses and disclosures of PHI as those of the patient. HIPAA permits an exception if the organization has a reasonable belief that the personal representative may be abusing or neglecting the patient, or if there is the potential for endangerment of the patient by allowing the individual to be deemed the personal representative.

Amendments Patients have the right to amend their PHI, if they can substantiate that the information is inaccurate or incomplete. The organization has the right to deny such a request, but must do so in writing and allow the patient to submit a statement of disagreement, which should be incorporated into the record. An organization may also receive a request from another health care provider to amend a record, which would be subject to the same rule.

Medicolegal The authors were unable to find any literature or specific legal cases directly related to patients having open access to their medical records. Macros and templates used by providers in EHRs may aid in defensive documentation. However, many would complain that usage has resulted in superfluous negative findings and a less meaningful narrative. Finding this balance remains a challenge for providers.⁶

CONCLUSION

Releasing notes to patients can be done in varying ways, and should be considered as a potential way to improve and increase patient engagement as well as potentially improve quality of care. Neurologists should consider the 5 Ws when planning a note release program: why, who, what, when, and where. They should be aware of their audience when documenting sensitive material such as devastating diagnoses and genetic information. Future considerations include bidirectional notes, where a patient is allowed, even encouraged, to add additional information to the note, either before or after the visit is completed. Previsit questionnaires, completed by the patient on the electronic patient portal, could be used for this purpose.²¹

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