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NIH Clinical Safety Rounds

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Whose Progress Notes Are They, Anyway?

There may have been a time long ago in school when, perhaps, you passed notes with the intent to keep the information contained within a secret. Some of us today continue to communicate in secret, or otherwise in the secret code of medicalese, about the status of our patients via their progress notes. Our habitual impulse, it seems, is to not share these notes with our patients.

The reasons are many: Progress notes can contain extraneous information we think the patients don't need to see; some notes contain lab results too dense for mere mortals to process; some notes are just plain sloppy with their cut-and-paste sections from previous notes, confusing time and place of procedures. You may be concerned that sharing these notes would interfere with your well-established workflow and cause worry or confusion among your patients.

Yes, there's cause for caution when releasing notes. But we need to ask ourselves, Whose progress notes are they, anyway?

We all know the answer to that question. That is why, starting in July 2019, most of our patient volunteer progress notes will be immediately available to patients via the patient portal. This should provide enough lead time for us to get better at making coherent progress notes. And this will be a win-win for patients and care providers.

For patients, easier access to their progress notes may improve engagement with their care providers and encourage patients to take greater ownership of their health and to participate in shared decision-making. For care providers, this will encourage us to think more deeply about the information we provide. The discipline needed to make notes more understandable can lead to greater insight to the best care options, as well as flag erroneous information and potential risk of harm.

The community is moving in this direction. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 granted patients the right to view their personal health information. The internet age then gave birth to patient portals, now ubiquitous in healthcare. Patient access to progress notes was the next logical stop. The Robert Wood Johnson Foundation funded an exploratory study in 2010 to examine the pros and cons of accessible progress notes, recruiting more than 19,000 participants. As published in the Annals of Internal Medicine in 2012, "Patients accessed visit notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and virtually all patients wanted the practice to continue. With doctors experiencing no more than a modest effect on their work lives, open notes seem worthy of widespread adoption." (See Delbanco et al., PMID: 23027317).

You're a fact-driven bunch, and I encourage you to review the literature to learn of the benefits of making progress notes accessible. It's the right thing to do, and the time to act is now…to be ready by July.

– James Gilman, M.D., NIH Clinical Center CEO

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5 Things to Know This Issue

1. The Hospital Board: The Clinical Center Research Hospital Board met on February 1. All presentations are posted at https://ccrhb.od.nih.gov/meetings.html, and the videocast is archived. Spoiler alert: It's mostly good and inspiring news…with an abbreviated agenda!

2. News from the hood: The Pharmacy Department would like to remind staff that it regularly conducts extensive hood cleaning on Saturday night into Sunday morning, roughly midnight to 2 a.m. During this time, the floors are wet, and the cleaning odors are strong. As such, the Pharmacy is significantly limited in the services it can provide. Please remind your staff to get your overnight orders in early, particularly if you expect a drip to run dry during these witching hours.

3. Patient satisfaction high and steady: Approximately 85 percent of NIH patient volunteers have reported that their experience at the Clinical Center as inpatient or outpatient study participants have been positive over the last two years. This is compared to ~73 percent to the HCAHPS and NRC benchmarks of other hospitals. That said, 90 percent would be nice, as would 100.

4. Lots affected: The Pharmacy Department experienced a still unexplained warming of its walk-in investigational drug unit over a weekend in early February, affecting 270 lots. With much scrambling, the Pharmacy was able to move the meds within two hours, minimizing damage to the drugs and the associated protocols. Had the refrigerator they moved the meds to, in the CRC, failed, many protocols could have been compromised. We need to consider a better back-up plan should the unexpected strike again.

5. Three appointments, minus one: Suzanne Wingate, Ph.D., R.N., the clinical director of the National Institute of Nursing Research, is the new chair of the Medical Executive Committee. Jonathan Green, M.D., is the relatively new director or the Office of Human Subjects Research Protections (OHSRP). Norman "Ned" Sharpless, M.D., was selected as chair of Clinical Center Governing Board (CCGB), replacing the late Stephen Katz, who left an incredible legacy in his service to the NIH community and patient safety and care. However, Sharpless has been called away to serve as acting commissioner of the FDA, and a new CCGB chair has not yet been chosen.

From the Patient-Safety Huddle…

Reps from CC departments and NIH Institutes convene daily at 8:40 a.m. in the Medical Board Room to report on concerns from the previous 24 hours, as well as to look forward to any potential safety or quality issues expected in the next 24 hours. Here are a few things we're tracking from recent huddles:

**** Saving face:*** Medical students on rounds have been known to faint, perhaps a result of the sheer exhaustion from the "information overload" in this early-morning event coupled with not eating a nourishing breakfast or the emotional stress of interacting with very ill patients. Recently one medical student fell so hard that he injured his face and needed to be taken to Suburban Hospital. If you work with students on rounds, please keep an eye out for their well-being and remind them to eat and rest well.

**** Gut feeling, stay home:*** A staff member began to manifest the symptoms of a GI illness at work but not until after coming in contact with patients. We admire your work ethic, but if you feel sick, stay home. The Clinical Center has many patients who are immunocompromised. They cannot be served well by your working if you carry harmful contagions.

**** Uncommon diseases require uncommon drugs:*** A patient with multidrug-resistant TB missed the first morning dose of an antibiotic, cycloserine, but did receive the planned second dose in the evening. The reason for the miss was that the drug was rare, not used at the Clinical Center in the past year, and fell off the eligible drug list during that time, thus never delivered. Indeed, the administered dose was borrowed. We need to understand why a drug on the World Health Organization's list of essential medicines could not be procured quickly.

**** I got your back…and blood:*** Hearing that the Phlebotomy Service was short on staff, OP12 stepped in to take some of the requests for blood draws. Nice teamwork.

**** Protocol upheld:*** We don't transfuse patients with platelets just to make them eligible for a protocol. Of course not. A STARS entry in February game some people that impression, however. A patient with a low platelet count received a transfusion to treat the underlying idiopathic thrombocytopenic purpura (ITP), independent of protocol eligibility. We must remember that the STARS is a surveillance system, not a final record of goings-on at the Clinical Center.

**** Check your guns at the door:*** NIH Police prevented a visitor from coming onto campus with a gun, which he was carrying lawfully. No firearms are permitted on the NIH campus. This is not an uncommon event. This time the interesting element is that the visitor was a Catholic priest.

**** In space, no one hears you buzz:*** A patient had a serious reaction to chemo, and the attending nurse hit the call-bell to get someone to help. Yet only those standing in the hallway would hear this; nurses in other rooms would not. Fortunately, there were nurses in the hallway. We need a better call system in place to remedy this potential patient-safety risk.

Deep Dive: Sepsis and Cytokine Release Syndrome

Taking a deep dive, at the request of the Hospital Board, CC staff set out to determine the 30-day crude mortality rate for sepsis. The measurement is a complicated one for hospitals because some patients die *from* sepsis while others die *with* sepsis. Sepsis is a life-threatening condition that occurs when the body's natural response to immune molecules released into the bloodstream to fight an infection becomes out of balance, triggering changes that can damage multiple organ systems. While sepsis can happen to anyone, the condition is most deadly in people with chronic diseases and compromised immune systems — that is, a large constituency of our patient volunteers.

The Clinical Center had 21 cases of severe sepsis and 5 deaths last year, a mortality rate lower than the national average. The signs and symptoms are well recognized: hypotension, elevated lactate, rise in creatinine and bilirubin, among other measures. Treatment is primarily with antibiotics and fluids. Interestingly, sepsis can look nearly identical to cytokine release syndrome, or CRS, a side effect of CAR T-cell immunotherapy. The Clinical Center is treating more and more cancer patients with CAR T-cell therapy…and thus becoming expert in recognizing CRS, which can be treated with tocilizumab, an immunosuppressive drug that blocks IL-6, a cytokine abundant in CRS.

To determine the sepsis mortality rate, the CC team tapped into medical records using BTRIS and searched for "vasopressor requirement" as a surrogate marker for severe hypotension, and then reviewed medical charts to differentiate sepsis from CRS. The exercise proved effective in helping the Clinical Center understand sepsis mortality vis-à-vis CRS. (We had no CRS mortalities last year!) With CAR T-cell therapy now FDA-approved, and with CRS being a significant and common side effect, hospitals nationwide will need to better differentiate sepsis from CRS, understand the effect on their patients, and act promptly in treatment with antibiotics or tocilizumab, accordingly.

In Motion: Steam Pipe Disaster

A series of steam pipe leaks in the ACRF detected early on Monday, March 11, severely limited activity in and around the clinics for two days. The clinical unit most affected was Surgery, which needed to postpone surgeries and procedures on March 11 and 12. Radiology, Laboratory Medicine, and all the clinics in the ACRF scrambled to provide what services they could, with no heat or hot water. All was back to normal by March 13…for most staff.

The heaviest burden is now on Materials Management, who are tasked with cleaning up the mess in the supply storage areas as they simultaneously assess what supplies are still viable. The steam and subsequent water damage have led to a significant loss of clinical supplies, and it may take months before the supply system returns to normal. Staff is instructed to pay meticulous attention to medical supply needs, particularly in those situations where outside consultants are scheduled. Make certain they have what they need before getting to the procedure room.

Staff once again rose to the challenge. Kudos to ORF, who worked through the night to fix and contain damage. However prepared we are to deal with calamity, the steam pipe disaster nevertheless points to the importance of budget resources for infrastructure improvements.

SuperSTARS: And the recipients are…

When you combine a super staff (the CC) with a clever name for a patient-safety alert system (STARS, short for Safety Tracking And Reporting System), it's only inevitable that someone will think about creating an award program called SuperSTARS. This award recognizes those who show commitment and dedication to improving patient safety and clinical quality at the CC — staff members who goes above and beyond to keep patients and employees safe, prevent harm, and promote a culture of patient safety. The recognition is tied to a STARS report, such as a "good catch" or a high-quality service event that goes beyond typical work duties. The bar is set rather high for this one. The awards, to be bestowed quarterly, come with a certificate, a gold star (of course), and a memo signed by CC leadership to be placed in the awardees personnel file. The latest group of SuperSTARS comprises:

- **Chauncey Buford, Materials Management**—Recognized for recovering Lammie, a treasured teddy bear and family heirloom passed from mother to child but inadvertently tossed in the laundry at the Clinical Center. Now, even a casual reader of Winnie the Pooh knows these bears a prone to adventures. Mr. Buford, the laundry supervisor, needed to act quickly and made numerous calls to track down Lammie, who was far from the Clinical Center when finally spotted. Lammie returned unharmed with stories to tell, albeit told only to the owner.
- **Maureen Higgins, Housekeeping**—Recognized for her positive attitude and intuition with patients. Ms. Higgins is a housekeeper on 3NW. She possesses the knack for knowing how to engage patients who want to be engaged and bringing out good spirits to those on the border, yet remaining pleasant but silent around those she can tell are not in the mood to be spoken to as she goes about her task of cleaning rooms. She told the patient-safety huddle attendees that she lives by the guiding principle, "Whoever you are… be noble. Whatever you do…do well. Whenever you speak…speak kindly. Give joy wherever you dwell."
- **Sun Young Moon, Pharmacy**—Identified an error in the Investigational Drug Management System (IDMS) label during the preparation of a study drug. Note that many non-FDA-approved drugs are denoted by a mishmash of letters and numbers. Ms. Moon noticed that the labelling on the vials did not match what came from the manufacturer, despite barcode scanning correctly. Because of Ms. Moon's close examination of all labels, in addition to the barcode scanning, the affected drug was pulled and relabeled correctly.
- **Carlos Alcantara, Patrick Alexander and Joshua Moore, Patient Services**—Recognized for strategic thinking, proactively identifying potential challenges, and executing a plan that led to a smooth transfer in an emergent situation. The three men assisted in the safe transfer of a patient from the NIH Cardiac Cath Lab to an outside facility via an air ambulance. Not knowing where the ambulance would enter, the three men strategically placed themselves around campus so that at least one of them would be present to assist the crew to the lab, to help maneuver the byways and hallways of NIH, and to direct the crew back to the ambulance. Their response was quick, thorough and calm, and it allowed for the patient to get the necessary care needed.
- **Kathy Myint-Hpu, Pediatric Consult**—Recognized for helping a pediatric patient in acute pain. The nursing staff was unable to reach the primary team for orders for pain medication and other interventions. Myint-Hpu, a nurse practitioner, overheard the commotion. She evaluated the patient and placed an order for STAT pain relief. She also sat with the mother, relieving her anxiety over the child's condition. This was not her patient and not her team, but Nurse Myint-Hpu saw a patient and other clinicians in need and immediately jumped in to help.

Outside Legal Requests for Expert Testimony in Non-Government Cases

The following is provided by the NIH Branch of the HHS Office of the General Counsel, a group of lawyers who serve as legal advisors to all of NIH, including the NIH Clinical Center.

Last issue we discussed what to do when an employee is contacted by an outside lawyer about something that occurred at work or something that involves one's Federal position. This time we'll discuss what to do if a lawyer requests you provide expert testimony in litigation for which the government is not a party and that does not involve something that arose in the course of your official duties.

In some instances, employees are solicited to provide "expert witness" testimony in a case in which the NIH does not have any affiliation with the plaintiffs or defendants (e.g., the patient was never seen on a study at the Clinical Center). This would be considered an outside activity, not part of one's official duties or views representative of your IC or NIH. Government ethics regulations require federal employees to obtain prior approval through their ethics official before consulting on legal matters or providing expert witness services. The analysis of each outside activity request is fact specific, and there are restrictions depending on the court and the parties. For more information please see the NIH Ethics Office's webpage on consulting with a law firm.

Questions about this topic or other legal matters? Contact OGCNIHBranch@nih.gov.

Key Patient Safety & Care Contacts

Safety Tracking and Reporting System: https://stars.cc.nih.gov
Patient Safety and Clinical Quality: ccpscq@mail.nih.gov
Clinical Center Anonymous Safety Hotline: 866-444-8811

A closing thought: "Honorable beginnings should serve to awaken curiosity, not to heighten people's expectations."
—Baltasar Gracián y Morales, Jesuit author (1601–1658)

The NIH Clinical Safety Rounds is produced by the NIH Clinical Center in partnership with the Office of Intramural Research. For more information or to suggest future content, contact ClinicalSafetyRounds@nih.gov.

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