Opening Notes Directly to Transplant Patients Under the Cures Act: Applying Lessons Learned

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Society for Transplant Social Workers Conference
October, 2021
No Conflicts

- ............to report

- Funding sources: Cambia Health Foundation, Gordon and Betty Moore Foundation, Peterson Center on Healthcare, Robert Wood Johnson Foundation
OpenNotes

- What is OpenNotes??
- What is OurNotes??
Goals

- Share our own, as well as the national experience, with fully open clinical notes, particularly in mental health.

- Notes as (narrative) therapy for behavioral health and mental illness.

- OpenNotes as a movement to create a culture of transparency and respect, especially in establishing partnerships with the patients we serve.
Always start with........

What is Best for the Patient??!!
Relevant BIDMC History

- Ethics Note Sharing Policy (20+ years)
- Sharing Notes in Mental Health (35+ years)
- Culture of Transparency and Trust
  - Apology and Disclosure
  - Preventable Harm Initiative
21st Century Cures Act

- Effective April, 2021!
- Requires Direct Patient Access to their Electronic Medical Record, really OpenNotes!
- Forbids “Information Blocking”!
- Mental Health ("Psychotherapy Notes") had been viewed as excluded but really appears to be included………
- Complete record access through third party apps to be provided by 10/22!
- Prior to Cures Act, 55 million patients in USA participating in OpenNotes with 25% having opened up mental health notes for 3+ years
21st Century Cures Act

Achieving Information Equity

HIPAA catching up with the computer age

Patient Autonomy (Undue?)

Paternalism

Professional Autonomy and Integrity
We miss a critical opportunity to build trust and advance equity!

- Trust is essential for:
  - Following care plans and other clinical advice
  - Getting recommended vaccinations (!)
  - Clinical trials (!)
  - Telehealth (!)
  - And establishing any relationship!!
Federal “Preventing Harm Exception”
(See 45 CFR § 171.201)

- There are 4 scenarios in which a provider may block information under the “Preventing Harm Exception”.
- Under **each** of these 4 scenarios:
  - The provider must reasonably believe that blocking access to information will **substantially reduce the risk of harm to the patient or another person**.
  - Blocking access to information should be **no broader than necessary** to substantially reduce the risk of harm.
Information Blocking

- Groups/Classes of Persons Issue

- If “covered actor” with electronic health information, then the Rule requires you to make it available
Federal Exceptions
(See 45 CFR § 171.201)

- Content and Manner Exceptions
- Substantial Harm...............Physical Harm
- Privacy Exception
Federal Exceptions
(See 45 CFR § 171.201)

Do Social Work Transplant Evaluations fall under the exceptions for ‘blocking’?

And is there a difference if the transplant is ‘life saving’ vs ‘life enhancing’?
Social Work Transplant Evaluations

- Ethical Considerations:
  - Beneficence
  - Non-Maleficence
  - Duality
  - Loyalty
  - Distributive Justice
Social Work Transplant Evaluations

Your professional obligations:

To the patient? Their loved ones? Your clinical team? To the organ donor?
Social Work Transplant Evaluations
Three Principal Questions

▪ Would OpenNotes help patients become more engaged in their care?
▪ Would OpenNotes be the straw that breaks the clinician’s back?
▪ After 1 year, would patients and clinicians want to continue?
Behavioral Health Roll Out

1. BIDMC Psychiatry Department- 3/1/14 start
   Opt-in Model: 10 patients apiece

2. BIDMC Social Work Department- 4/1/14 start
   a.) Opt-out Model: All patients in unless specifically excluded or
   b.) Ramp-up Model: Start with smaller cohort and build up
Staff

- 15 Psychiatrists/Therapists In Psychiatry Department

- 28 Social Work Therapists agreed to pilot; 4 declined; pediatric therapists and fellows excluded; staff turnover; or no eligible patients = 24 started

- 440 patients at start; Currently better than 5000 participating in open therapy notes and includes all
Common Concerns about Open Notes in Mental Health:
OpenNotes causes harm!!
BIDMC Clinical Staff Fears:

1. Increased Work Burden—"feeling a sense of pressure to get notes entered in a timely manner so that they can be useful to the patient"
BIDMC Social Work Staff Fears

1. Increased Work Burden—”feeling a sense of pressure to get notes entered in a timely manner so that they can be useful to the patient”

2. Misunderstanding: “I’m concerned about patients misunderstanding information in the notes…….”
BIDMC Social Work Staff Fears

1. Increased Work Burden—”feeling a sense of pressure to get notes entered in a timely manner so that they can be useful to the patient”

2. Misunderstanding: “I’m concerned about patients misunderstanding information in the notes......On the other hand, I am hopeful that the open notes may actually enhance the therapy process and promote greater communication/understanding on both sides.”
BIDMC Social Work Staff Fears

3. Re-languaging Notes and Processing of Notes-

“....will they be angry about certain content?!”
We will have to change our notes, possibly double chart, and important information will be lost!
4. Patients with severe mental illness, especially psychosis and paranoia will flee

5. “It’s one thing to tell them in session we think they are having paranoid thoughts and another for them to read it at home alone”
Therapist Work Group:

- FAQ’s and scripts/info sheets developed
- Anticipating reactions or feedback from patients and colleagues and staff
- Thesaurus approach for altering language
What did we find..............???
Patients were pleased…

• And they…………..
  - want their notes!
  - are not scared stiff!
  - read the notes!
  - share the notes!
  - report important benefits!

Patients with ‘adverse effects’ tended to clarify these concerns as underlying concerns such as privacy or already existing issues; or misinterpreted questions when asked.

Biggest issue, as in medicine, seems to be whether there is concordance between what the therapist says in session and what they write in the note.
Note Reading

- The vast majority of patients never mentioned to their therapist about having read their notes.

- Note Reading drops off due to redundancy.
18% shared notes with others (20-42% in medicine), mostly family
The NIGHTMARE Patient!!

Recurrent staff concerns about the “nightmare patient” reported at BIDMC, as well as other practices…….
The NIGHTMARE Patient!!

Is this really an index for ‘contagious’ staff angst???

These are labor intensive patients irrespective of the therapeutic interventions............!
Patient who Regresses

- Reads her notes and increasingly paranoid
- Group therapy
Less Than Honest Transplant Patient

- Ethics Consultation:
- Living situation not accurate
- Ability to get to/from appointments not accurate
“Good news — they found you a donor for a smile transplant!”
Transplantation Cases:

1. John is severely injured through an explosion. He suffers severe mutilations to his body and struggles with Post-Traumatic Stress Disorder. John is in his late 20’s.

2. Jane had a history of serious illness with cervical cancer. She also suffered an eye injury from an explosion. Jane is in her late 20’s.

3. Kevin is 7 years old and has severe disfiguring injuries, especially to his face, as well as many adjustment issues.
Transplantation Cases:

1. John would like to be considered for an arm transplantation as well as a penile transplantation.

2. Jane would like to be considered for a whole eye transplant as well as uterine transplantation.

3. Kevin’s parents would like him to be considered for a facial transplantation.
The Trolley Problem:
The Trolley Problem, Part 2:
The Trolley Problem, Part 2:
Why The Difference???

J. Greene, R. Brian Somerville et al
The Trolley Problem

- **Why the Difference??**
- An internet-based survey of the dilemmas was presented to a wide variety of people.............
- Over 200,000 people
- Over 120 countries
- Identical results regardless of gender, countries, educational levels, ages, income levels, political affiliation, religious affiliation
- Results:
  - 90% throw the switch
  - 10% push the very large person
  - Can’t explain why...Rational explanations insufficient
  - Points to a universal human principle about moral reasoning?
Distributive Justice Issues

Organ Scarcity

.........................Precious Gift!
Transplant Cases:

John’s injuries from the explosion were from an Improvised Explosive Devise (IED) in Afghanistan while he was serving his country in the military

Verses…………
Transplant Cases & The Rule of Rescue

John’s injuries were from his Meth Lab exploding which he and his wife Jane were operating as part of their drug dealing efforts.

And what if Jane’s uterine trauma was due to the meth lab explosion instead of from cervical cancer?

And what if Kevin is their son who was caught in the blast! Or Kevin is an undocumented person, as are his parents?
Open Notes

How will you document?

Can/should you block the note?

Does it meet criteria for blocking?
“Self-Inflicted” Health Issues

Create a very different response..........................to scarce resource allocation issues
OK, so WHERE'S THE COURAGE KEPT?
Life Saving Transplants

Sickest plus Survivability

Loyalty to Recipient and to Donor

Organ as a Gift to be Treasured
Two Patients who Prints Out Notes

- Unable to recall what was talked about in session
- One prints out note to review regularly
- Other declines looking at note for some time
Delusional Patient

- Couple’s Therapy
- Belief that smoke/carbon detectors are bugged
Patient Struggling with Depression

- “Declined” reading notes for 2 ½ years
- “I’d be petrified to look. I’m not gonna do it.”
- Convinced notes will affirm his being a “horrible” person
Looking Under the Hood

"It's just upset."
The Bottom Line

- Better than 80% of patients *wanted to continue* to be able to see their visit notes online.
- Better than 60% of patients said availability of open notes *would affect their future choice* of a therapist.
- *Not one therapist or patient asked to stop*
- *And now..........................*
Patients with Severe Mental Illness Study (Blease et al, 3/21, JAMA)

- 136,815 patients with Bipolar D/O, Schizophrenia or Major Depression; 29,656 responded (22%)

- 67% reported being helped to understand why their med(s) were prescribed

- 65% reported feeling more comfortable with taking their med(s)

- 60% reported feeling that reading their note(s) helped to answer their questions
Lessons Learned

- **70/30 Rule**
  - Delivery of Difficult News ~ 70+% with solid metastatic cancer unaware of chemo’s palliative intent

Lessons Learned

- 70/30 Rule
- Stigma, especially in mental health!
  Mainstream!!
Lessons Learned

- 70/30 Rule
- Stigma, especially in mental health! Mainstream!!
- Professionals Fears: looking foolish or incompetent

- Active vs. Passive Utilizers!
Transparency, Trust, Respect and Relationships

Facilitates...
- Engagement
- Adherence
- Acceptance

Transparency → Honesty → Therapeutic relationship
Respect ← Trust
Privacy vs Confidentiality

18% shared notes with others (20-42% in medicine), mostly family
Communication
Engagement
Trust

What is Best for Our Patients?!
Pragmatic Considerations
How Can Sharing Behavioral Health Notes Help Patients??

- Demonstrating respect and reducing stigma
- Empowering patients
- Organizing care and tracking progress
- Providing a tool for behavior change
- Enhancing trust and the therapeutic relationship
- Making care safer
- Potential for reducing workload

Source: https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/
Writing Open Notes Tips

- First and foremost................

Always write your note as if the patient is looking over your shoulder!!

Avoid ‘surprises’
Writing Open Notes Tips:

- The invitation is important
- Promote transparency
- Use plain, and supportive, language
- Engage patients in the documentation process, especially with ‘sensitive’ info
- Develop options if a patient’s access to notes may carry more risk than benefit
- Discuss the diagnosis

Source: [https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/](https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/)
Writing Open Notes

Tips

- Domestic Violence and Safety Exclusions
- PTSD - Lessons learned about setting expectations
- Who is ‘note’ intended for? Would OpenNotes adversely effect teaming communications?
- Obsessive patients (“I’ve spent my whole life learning not to double think.”; “When I go to my mechanic, I don’t want to look under the hood. Same here!”)
- Paranoid patients (“I’d be petrified to look. I’m not gonna do it.”)
- Patients “in denial” and ‘premature’ info

Source: https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/
Challenging Situations:
The delusional patient

- Mr. A is a man with schizophrenia who believes that the FBI has placed “invisible” microphones and cameras in his apartment. He takes 1 mg of risperidone daily “to keep my family off my back,” but you are trying to get him to take a higher dose. You have tried to discuss his diagnosis with him, but he dismisses it, and believes that “schizophrenia Scenario: was made up by the FBI to incarcerate subversives.”

- Sample note: Mr. A says he is taking risperidone 1 mg daily, but continues to be convinced that the FBI is monitoring him. We disagree on this, as we do about whether he has a psychiatric problem in the first place. I believe that a higher dose of risperidone would help him with the anxiety he feels about being monitored, but he firmly refused to increase the dose to 2 mg daily. I nevertheless urged him to consider a brief trial of the higher dose, to see if he noticed any benefit. We will continue to assess his overall level of anxiety and how it affects his daily functioning. I am concerned that his anxiety limits his ability to feel safe on a day-to-day basis. But on a happier note, he continues to be very interested in current events and reads newspapers and books extensively.
Challenging Situations: The borderline patient

- **Scenario:** Ms. B is a young woman who frequently self-mutilates to manage stress. She is taking fluoxetine and aripiprazole for anxiety and depression, which help to increase her stress tolerance to a certain extent, but she finds that ongoing use of alcohol and marijuana “help me more” with anxiety. Her relationship with her boyfriend continues to be marked by frequent verbal fights, and occasional pushing. You are trying to explore other medication options and also to encourage her to try dialectical behavior therapy.

- **Sample note:** Ms. B’s condition remains about the same as it was during our last visit. She feels the medication helps somewhat, but I have shared my concerns with her that her continued use of marijuana and alcohol likely interferes with the ability of the medication to help. She recognizes her frustration and unhappiness, however, and was open to discussing a referral for dialectical behavior therapy. I think this could be very helpful for her. I also raised the question of AA. We agreed to see how she felt after a week of going without alcohol, and if she can do this we will consider a low dose of lithium to help her with her moods. While she has her ups and downs at her job as a receptionist, she does feel her boss is supportive, and that’s encouraging.

Source: [https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/](https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/)
Challenging Situations: The survivor of sexual trauma

- **Scenario:** Ms. C is a woman in her thirties whom you have seen for a year for depression and who now reveals that she was molested by an uncle several times when she was 9. She has never revealed this to anyone before and was overwhelmed with feelings when she mentioned it. She asks you not to reveal this in the medical record.

- **Sample note:** Ms. C is functioning well on citalopram 40 mg qd, sleeping and eating well, and doing well at work. Today she mentioned some incidents in her past that we have not discussed before and that were very significant for her. We will continue the citalopram and explore the incidents when we meet next.

Source: [https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/](https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/)
Challenging Situations: The dishonest patient

- **Scenario:** Mr. D. is a man in his twenties whom you have been treating for anxiety. You get a call from a pharmacy saying he has been filling prescriptions for a benzodiazepine from a physician you have never heard of. You tactfully confront Mr. D with this information and he gets very upset and leaves the visit prematurely, saying he can’t trust you anymore.

- **Sample note:** Mr. D. said he has been doing well on fluoxetine 20 mg qd and clonazepam 1 mg bid for anxiety, and that he enjoys his new job as a mechanic. I told him I had been contacted by a pharmacy to ask me if I knew he was getting alprazolam from a different doctor, and I asked him if we could discuss the issue. Unfortunately, he became very upset and told me that the alprazolam was “none of your business.” I told him I thought perhaps his anxiety was undertreated on the regimen I have been giving him, but he did not want to discuss it, and left the office suddenly. He did not make a follow-up appointment, and I will send a letter inviting him to do so.

Source: [https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/](https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/)
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O’Neill, S “Flattening the Mental Health Curve During the Pandemic” *Social Work Voice* 3:4, 8-9 2020


Klein JW, Peacock S, Tsui JI, O’Neill SF, DesRoches CM, Elmore JG. “Perceptions among Patients with Mental Health Diagnoses About Reading Psychiatric Primary Care Clinic Notes” *Annals of Family Medicine*. 16: 4: 343-345, 2018

Whyte, R and O’Neill, S “Disclosures in Surgical Care: Errors, Surgeon’s Experience, Conflicts of Interest, and Truth Telling” in *Ethical Issues in Surgical Care*, American College of Surgeons, 2017
Thanks!
Questions??

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