Session Two and Three:

Expanding Patient Access to Health Records

Moderator: Kenneth W. Goodman, PhD, FACMI, FACE
Presenters:

- **Jeffrey P. Broscos, MD, PhD**
- **Stephen F. O'Neill, LICSW, BCD, JD**

EXPANDING PATIENT ACCESS TO HEALTH RECORDS

Clinical Ethics in the EHR Era

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UHealth Pediatrics
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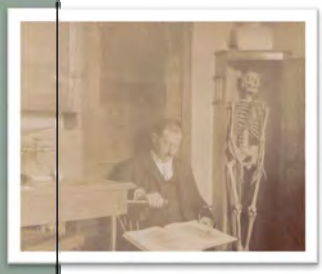
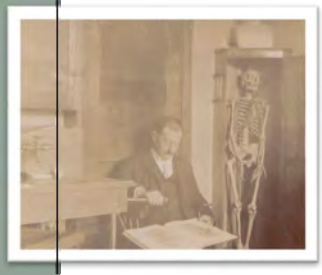
UNIVERSITY OF MIAMI
MILLER SCHOOL of MEDICINE

Disclosures

- Employment and Positions
  - University of Miami
  - Jackson Health Systems
  - Director,Title V CSHCN, Dept. of Health, Florida
  - Advisory Committee on Hereditary Diseases of Newborn and Children (HRSA, MCHB)
- No disclosures re conflict of interest
  - No commercial interests
  - Medical-legal testimony (not related to topic today)



History of Health Care in US



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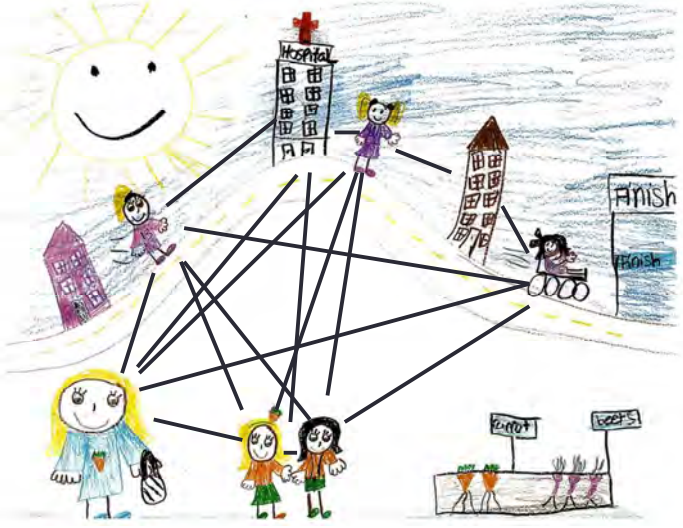
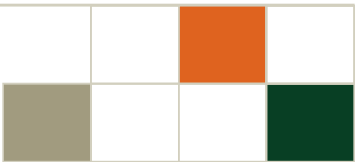


Outline

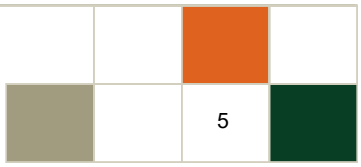
1. Electronic Health Record (EHR)
   – the good, the bad, the reality
2. Some clinical ethics issues
   a) Confidentiality vs. convenience
   b) "Special" confidentiality of mental health notes
   c) Adolescents – sex, drugs, and rock & roll
3. Open notes (Steve O'Neill)



EHR - good

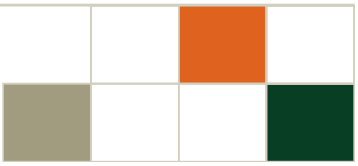
- Access to information (providers, patients, location, images)
- Analysis of information (individual patients, clinical populations – QI, value-based care)
- Research: "Population-based cohort study using Danish nationwide registers. Participants were all individuals born in Denmark between 1/1/95 and 6/30/12 (N = 1 098 930)."

Kohler-Forsberg, *JAMA Psychiatry.* 2019;76(3):271-279



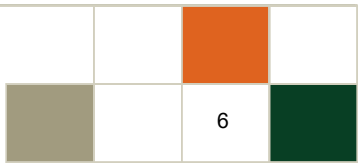
EHR - bad

- Access to information (e.g., the Internet)
- Analysis of information (painfully limited)
- Too much information, and very little wisdom
- Time spent on “clicks”
- EHR systems not connected to each other
- “i-Patient” – Abraham Verghese
- _____ (fill in)



EHR – some reality

- EHR is here to stay; let’s make it work
  - “Singing in the Rain”
- EHR superimposed on a fractured, dysfunctional health care “system” in US
  - Decentralized; No one is in charge
  - Expensive
  - Competition



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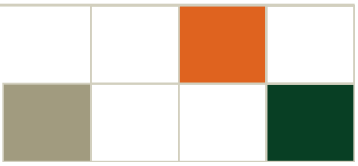
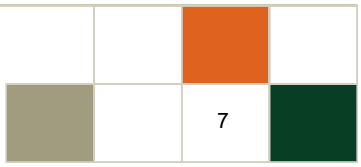


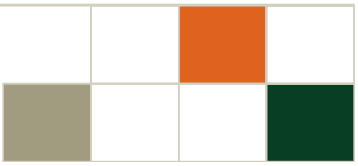
EHR Clinical Ethics – What's new?

- In some ways, not much: in the same way that the EHR reflects the good and bad of medicine in the U.S., many "EHR clinical ethics" issues are not new
- Hippocrates "Sacred secrets" and ancient issues about trust



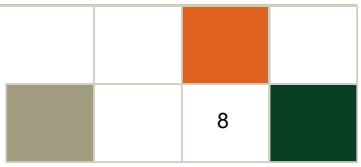
Terms: Privacy and Confidentiality

- Privacy
  - desire/ability of an individual or group to seclude themselves
- Confidentiality
  - actions that health care providers/system takes to keep private information safe



a. Confidentiality vs. Convenience

- How many of you have emailed or texted your physician or nurse practitioner?



Confidentiality vs. Convenience

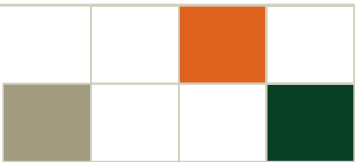
- How many of you would like to email or text your physician or nurse practitioner, if you could?

"Tyranny of Convenience"

- Technology is driving/driven by our increasing need/desire for convenience
  - We want it now
- To the degree that information transfer is protected, it is less convenient
  - Problem of hackers, ransom, etc.

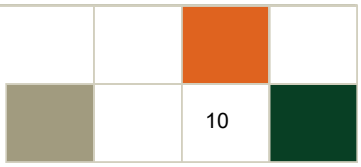
What Do You Think?

- **IMPORTANT MESSAGE FOR PATIENTS AND THEIR FAMILIES**
- Patients and families who use email (or text) to send me clinical information should understand that these methods of communication are not secure. For maximum protection of your privacy, please use U.S. mail, fax (above), or MyUHealth (https://myuhealthchart.com/mychart/).



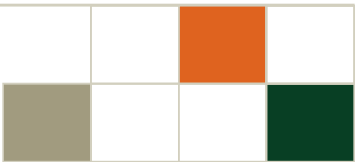
b. "Special Confidentiality" re Mental Health

- "Health" clinicians cannot read "mental health" notes in many EHR systems
  - Should license (state law) make a difference re availability of information?
- Get Smart - video clip
- https://www.google.com/search?q=get+smart+cone+of+silence&rlz=1C1CHFX_enUS595US595&oq=get+smart+cone+of+&aqs=chrome.0.0j69i57j0l4.3136j0j8&sourceid=chrome&ie=UTF-8



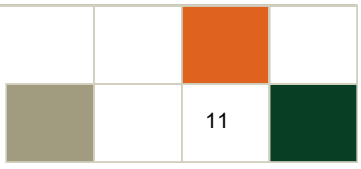
Adolescent Health Care

- Health issues related to sex, drugs, other behaviors
- Teens can be more open with providers if promise of confidentiality ("trust" matters)
- Until age 18 years, parents/guardians provide consent to care, which requires information
- State law allows adolescents to consent to some sorts of health care, with promise of confidentiality
- Leads to many clinical ethics issues



Adolescents in the Age of the EHR

- Parents have always had access to medical record (challenge of documentation)
- Now we are debating parental access through EHR portal
- Related issue: consent to contact for research
  - Who consents?
  - Whom do you contact first?



Open notes (Steve O'Neill)

- More later?

Open Notes: historical (and psychological) context

- History of patients with power, then "beneficence," now autonomy
- Professional role/Power/Control/Trust
- e.g. Words we choose in our notes
  - "reports" instead of "complains"
  - "reports no" instead of "denies"

Beth Israel Deaconess Medical Center

A teaching hospital of Harvard Medical School

OpenNotes

Ethical Dimensions of Opening Up Our Notes Directly to Patients

Steve O'Neill, LICSW, BCD, JD
Social Work Manager for Psychiatry and Primary Care
Associate Director of Ethics Programs
Behavioral Health Specialist for OpenNotes Program
Beth Israel Deaconess Medical Center

Faculty, Center for Bioethics
Instructor in Social Medicine
Harvard Medical School

Florida Bioethics Network
April, 2019

No Conflicts

- .....to report
- Funding sources: **Cambia Health Foundation, Gordon and Betty Moore Foundation, Peterson Center on Healthcare, Robert Wood Johnson Foundation**

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What is OpenNotes?

3

What is OpenNotes?

- **Everyone on the Same Page**
- OpenNotes is the international movement that's making health care more transparent. It urges doctors, nurses, therapists, and others to invite patients to read the notes they write to describe a visit. We call these opennotes.

4

OpenNotes

- And should we include Bioethicists??!!

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Goals

- Examine the ethical issues around transparency through opening up our notes
- Share our experience, locally and nationally, with fully open medical records (9 years), especially mental health (5 years)
- Describe OpenNotes as a movement…… including whether it helps/hurts transparency, trust and partnership!

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Common Concerns about OpenNotes in Mental Health

OpenNotes Causes Harm!!

What about our obligation to “Do No Harm” (Non-maleficence)??

And what about our ethical obligations to do our best by our patients (Beneficence)??

Destroying the Clinician's Fiduciary Relationship

- "Ruining Psychotherapy" (NYTimes, Washington Post, Chicago Tribune, Los Angeles Times, etc - public comments after articles)
- Clients entrust us with their 'secrets' and we have an ethical obligation to safeguard the best interests of our clients

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yipyap jardine1678 • July 7, 2014

This sounds like an interesting concept that could prove helpful in some instances but....might there start to be instances where certain therapists know that all their patients will have complete access to their own records, anytime they want? And if so, might the therapists self-censure, if only because they fear that if the patient were to read certain insights from the therapist, that it could cause the client to withdraw, become more closed-up during sessions, become angry, feel let down by the therapist, or worse, want to exact violence on the therapist?

Dagwood San Diego • July 7, 2014

Can't say I approve. Therapists will be writing "to the client" now, which may not be the content best suited to best treatment. Psychotherapy is a demanding and sophisticated art, with it's own language and understandings. This project disrespects it and may not be the best for the clients. Therapists should speak freely with clients and be transparent that way, in language shaped for each client, without robbing the doctor of her need to codify clinical material.

danny dude california • July 7, 2014

not everything a therapist writes is countertransference. However, showing EVERYTHING you write to your client is a great way to solidify transference and ensure it can never be fully addressed.

Why not just tell them everything we think as soon as we think it?

The answer is: because that's not clinically sound. Neither is this.

Susan Weston CT • July 7, 2014

Therapists already are actors, playing roles of fantasy parents, wise gurus, omniscient authorities. They can encourage clients to fixate on their innermost wounds and self-doubts, reinforcing powerlessness. Now, in providing the adult report cards. therapists create yet a new layer of infantilization and paternalism.

I'm confused how this adjudicator-supplicant role play paradoxically leads to autonomy and authenticity.

Susan Piedmont, CA • July 7, 2014

This will lead to a two charts situation. One, the old chart, is now the "letter to the patient" chart. The other, which will be secret, will be the real chart, to guide the therapist in treatment.

Christopher Simmons Marina del Rey, CA • July 8, 2014

It seems to me that if therapists are aware that their notes may be read by the patient that the therapists may feel pressure to write things that please or reassure the audience rather than write down pure, unbiased information about the patient's condition. Could this lead to two sets of notes, one (official) set that is geared toward encouraging the patient and another (secret) set where serious doubts and concerns are expressed without sugar-coating them?

sfdphd San Francisco • July 7, 2014

Depends on the patient. I'm fine with the people who are rational seeing my notes, but the ones with anger management issues, psychotic features, and personality disorders will have serious reactions to such information. They have trouble handling their own reality, let alone the view of the therapist.

Darker LI, NY • July 7, 2014

It seems that academics competing to "innovate" and generate publicity, have gone on a highly questionable route. Their careeristic vanity and narcissism is not appreciated.

Relevant BIDMC History

- 1972 Patient Bill of Rights
- 1976 "Orders Not to Resuscitate": NEJM
- 1986 First Electronic Health Records (Warner Slack, MD and Howard Bleich, MD)
- 1991 Mental Health Notes On-line within fully integrated medical record
- 1998 Ethics Support Service begins
- 2007 Preventable Harm Initiative
- 2010 OpenNotes starts in Primary Care
- 2013 All Medical/Surgical/Specialty notes opened up
- 2014 Preventable Harm to Respect/Dignity Initiative
- 2014 OpenNotes for Behavioral/Mental Health starts

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Relevant BIDMC History

- Ethics Note Sharing Policy (20+ years)
- Sharing Notes in Mental Health (5+ years)

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Relevant BIDMC History

- Culture of Transparency
- Culture of Respect

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Transparency in Health Care

- Definition
- Connections to other values
- Types of transparency
- How we're doing
- Why we should value transparency
- Charting a path forward

(Lauge Sokol-Hessner, MD BIDMC slides)

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Defining Transparency

The quality or state of being…

- free from pretense or deceit : frank
- easily detected or seen through : obvious
- readily understood
- characterized by visibility or accessibility of information especially concerning business practices

https://www.merriam-webster.com/dictionary/transparent

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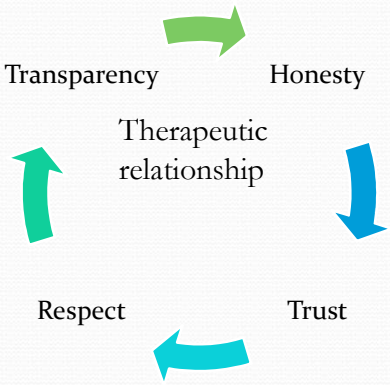
Transparency, Trust, Respect and Relationships



Facilitates…

- Engagement
- Adherence
- Acceptance

Transparency in Health Care

- Definition
- Connections to other values
- Types of transparency
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Transparency with Regards to What?

The information patients need to make informed decisions about their care

- Diagnosis, prognosis, and treatment options
- Quality of care
  - Performance measures
  - Harm events/errors
- Costs of care

AMA Code of Medical Ethics: https://www.ama-assn.org/delivering-care/transparency-health-care

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How Are We Doing?

Discussing serious illness

- Patients often don't understand their situation
  - ~70+% with solid metastatic cancer unaware of chemo's palliative intent
- Maybe in part because we often withhold information
  - Patients with cancer who wanted a survival estimate
    - 37% got a frank estimate
    - 63% got no estimate, or a conscious over or underestimate
- It's hard for us to be accurate
  - Longer patient-physician relationships can → greater error and optimism

Weeks et al., "Patients' Expectations about Effects of Chemotherapy for Advanced Cancer," NEJM 2012
Lamont and Christakis. "Prognostic Disclosure to Patients with Cancer near the End of Life." Ann Int Med 2001
Christakis and Lamont, "Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients: Prospective Cohort Study." BMJ 2000
Glare et al., "A Systematic Review of Physicians' Survival Predictions in Terminally Ill Cancer Patients," BMJ 2003

24

Why Should We Value Transparency?

Externally

- Enhance patients' trust and facilitate informed decisions

Internally

- Better engage clinicians and other professionals in improvement efforts
- Promote accountability among…
  - professionals for their actions
  - leaders for the system's design

Kachalia, "Improving Patient Safety through Transparency," NEJM 2013

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Why Should We Value Transparency?

Transparency drives us towards safer, higher-reliability care

- Preventing errors requires learning from errors
- It's not possible to learn from errors if they aren't discussed
- Room for improvement:
  - < 2/3 of hospitals' staff favorably perceive their hospital's openness in communication
  - < 1/2 report that their hospital responds to errors in a non-punitive way
- Respecting patient & professional privacy
  - Shame & blame are counterproductive, focus on fair & just culture
- Talking about other professionals' errors
  - Patients and families come first
  - Explore don't ignore
  - Institutions should lead

Kachalia, "Improving Patient Safety through Transparency," NEJM 2013 Gallagher et al., "Talking with Patients about Other Clinicians' Errors," NEJM 2013

Charting a Path Forward

With individual patients

- Professionals' communication skills (esp. w/serious illness)
- OpenNotes

At a system level

- Communication, apology, and resolution after harm
  - Massachusetts Alliance for Communication and Resolution following Medical Injury, 7th Annual Forum in May, 2019
- Continuing to tackle the challenge of price transparency
- Ongoing work to improve how we share quality data
  - Externally and internally

Externally Reported Preventable Harm at BIDMC

Hospital Acquired Central Venous Catheter Associated Bloodstream Infections (CLABSI)
Hospital Acquired Surgical Site Infections (SSI)
Hospital Acquired Ventilator Associated Pneumonia (VAP)
Falls Resulting in Injury
Acquired Pressure Ulcers/Soft Tissue Injury
Preventable Harm in Association with Providing Medications
Preventable Harm in Association with Surgery or Other Procedure
Other Preventable Harm in Association with Medical Care
Disrespectful Communication
Failure to Maintain an Environment that Preserves Dignity
Failure to Provide Appropriate Care After Death
Failure to Care for Personal Possessions

About the *OpenNotes* Movement

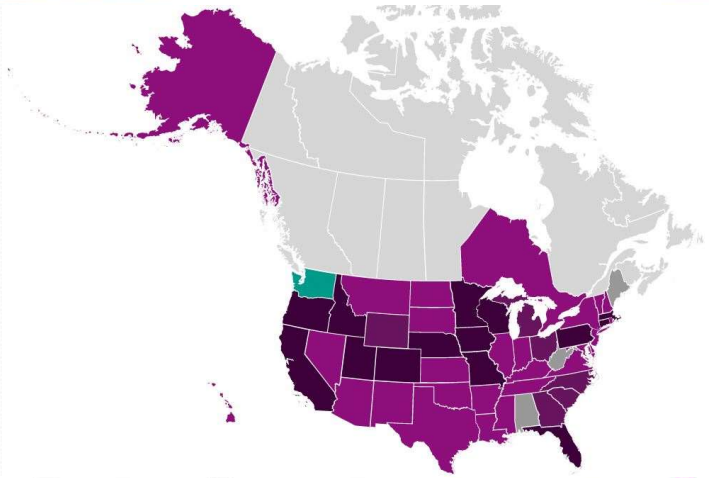
- Began in 2010 with 105 volunteer primary care doctors and 19,000 of their patients in Boston, at Geisinger in Pennsylvania, and Harbor View the Seattle inner city health care system in Washington state.
- The doctors invited the patients to read their notes via electronic portals
- Now, more than 40 million patients in the USA, thousands of doctors, nurses, therapists, trainees, physician assistants, case managers, and other clinicians are sharing notes

What's going on?

Beth Israel Deaconess Medical Center

UW Medicine HARBORVIEW MEDICAL CENTER

40+ Million Patients Have Access to Note



Map Key: = 0 institutions | = 1 institution (The Department of Veterans Affairs) | = 2-3 institutions | = 4-5 institutions | = 6-10 institutions | = over 10 institutions

Principal Questions

- Would OpenNotes help patients become more engaged in their care?
- Would OpenNotes be the straw that breaks the clinician's/therapist's back?
- After 1 year, would patients and clinicians/therapists want to continue?

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Always start with……..What is Best for the Patient??!!

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And Who Determines What is Best for the Patient??!!

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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

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Staff

- 15 Psychiatrists/Therapists In Psychiatry Department
- 28 Clinical Social Work Staff agreed to pilot; 4 declined; pediatric therapists and fellows excluded; staff turn over; or no eligible patients = 24 started
- 440 patients at start; Currently better than 4000 participating in open therapy notes

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BIDMC Therapist 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"

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BIDMC Therapist 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……."

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"I've written my diagnosis on this piece of paper. I'm going to slide it over to you, and I want you to tell me if you're interested."

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BIDMC Therapist 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."

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BIDMC Therapist Staff Fears

3. Re-languaging Notes and Processing of Notes- "….will they be angry about certain content?!"

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"

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Additional Issues:

- Domestic Violence and Safety Exclusions
- 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

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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

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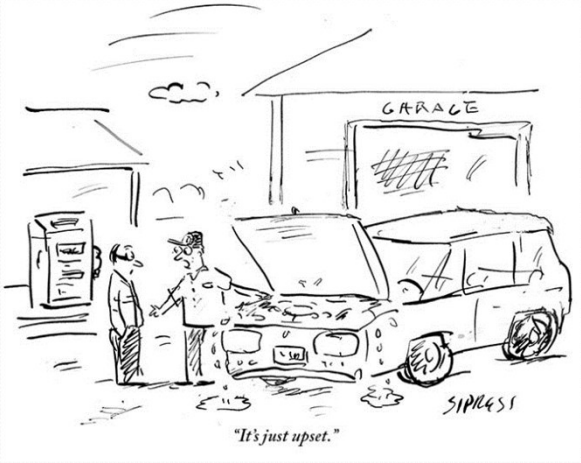
Looking Under the Hood



"It's just upset."

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What Have We Found??

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Patients were pleased…

They want the notes

They are not scared stiff

They read them

They share them

They report important benefits

Patients were pleased…

- Better than 90% of patients agreed that opening up therapy notes is a good idea!

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- Better than 85% of patients want to continue having notes available

Patients were pleased…

- Better than 90% of patients agreed that opening up therapy notes is a good idea!
- Better than 85% of patients want to continue having notes available
- Few patients said reading notes made them feel
  - Judged (Less than 15%)
  - Worried (Less than 10%)
  - Offended (Less than 5%)

Patients were pleased…

- Few patients said reading notes made them feel
  - Judged (Less than 15%)
  - Worried (Less than 10%)
  - Offended (Less than 5%)

- Veterans Health Administration Study (Denneson, L., Chen, J., Pisciotta,M., Tuepker,A., and Dobscha,S.; Patients' positive and Negative Responses to Reading Mental Health Clinician Notes Online, Psychiatric Services 69:5, May, 2018)
- Felt More in Control = 49%
- Feel More Trust in Clinicians = 28%
- Sometimes Experienced Stress or Worry = 26%
- Sometimes Felt Upset = 18%
- Often or Always Felt Upset = 8%

Patients were pleased…

- 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

Concordance in Bioethics Notes?

- Imagine what the effect might be if patients and their families/significant others could read your consult notes?

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Note Reading

- The vast majority of patients never mentioned to their therapist about having read their notes
- Note Reading drops off due to redundancy.....

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Privacy vs Confidentiality

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

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The NIGHTMARE Patient!!

Recurrent staff concerns about the "nightmare patient" reported at BIDMC, as well as other practices…….

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The NIGHTMARE Patient!!

Is this really an index for 'contagious' staff angst???

These are labor intensive patients irrespective of the therapeutic interventions…….!

55

The NIGHTMARE Patient!!

And in Bioethics, aren't nearly all of the consultations dealing with 'nightmare' situations?

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OpenNotes Patients reported important clinical benefits

- Better than 50% felt more *in control* of their care

57

Patients reported important clinical benefits

- Better than 50% felt more *in control* of their care
- Better than 50% reported *feeling better at self-care*

58

Patients reported important clinical benefits

- Better than 50% felt more *in control* of their care
- Better than 50% reported *feeling better at self-care*
- Better than 40% reported *better remembering* what working on in therapy

59

Patients reported important clinical benefits

- Better than 50% felt more *in control* of their care
- Better than 50% reported *feeling better at self-care*
- Better than 40% reported *better remembering* what working on in therapy
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60

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- Better than 50% felt *better able to trust* their therapist

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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 almost all have since joined.*
- *And now……..*

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2019 OpenNotes Survey

- 19 Networks with Mental/Behavioral Health notes opened up

- Patient Distress Issues since opening up?

  17 of 19 responded; 2 = inadequate experience

- "…we call the pilot "**the Big Yawn**"; we received no concerns or complaints from patients….." (4 years)
- "…..concerns are unfounded and patient complaints are very rare……(if concern arose) the patients discussed with their clinician. Sometimes the patient had a good point……. (3 years)

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Respect through Transparency and Accountability

- Patient Autonomy
- Parental Autonomy
- Professional Autonomy (vs. Paternalism)
- Respect and Dignity
- Loyalty/Fidelity
- Veracity
- Relationships/Partnerships

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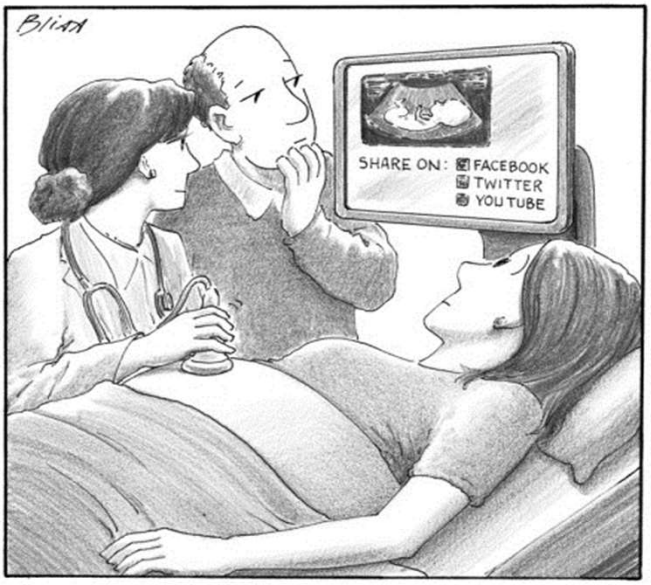

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Lessons Learned

- 70/30 Rule

66

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Lessons Learned

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

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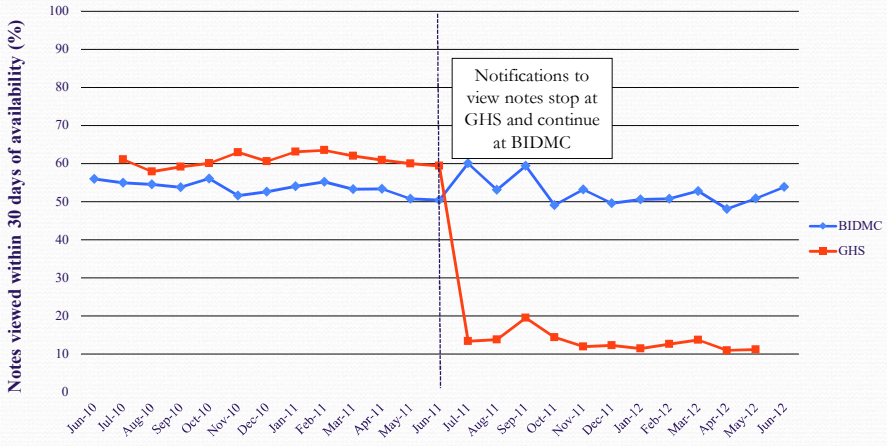
Importance of Notifications

Reading rates dropped when GHS stopped sending patients messages to let them know a new note was available



Communication

Engagement

Trust

...and the best possible outcomes

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99% of people
are **likely to feel the same**
or better about their doctor
after reading just one note

Bell SK, Gerard M, Fossa A, et al A patient feedback reporting tool for OpenNotes: implications for patient-clinician safety and quality partnerships. *BMJ Qual Saf* Published Online First: 13 December 2016. doi: 10.1136/bmjqs-2016-006020

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60-78% of those taking medications reported *"doing better with taking my medications as prescribed"*

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Ethical Framework and Analysis

- Establishing Common Goals of Care
- Sharing a Bioethics Consult Note

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What is the 'Expertise' of the Patient (or Surrogate/Proxy)?

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What is the 'Expertise' of the Patient (or Surrogate/Proxy)?

- Values
- ~~Wishes~~
- Preferences

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What is the 'Expertise' of the Clinician or Clinical Team?

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What is the 'Expertise' of the Clinician or Clinical Team?

- What is possible?
- And how best to achieve whatever is possible?

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Handling Difficult Ethical Judgments and Decisions

1. **Do the proposed benefits outweigh the proposed burdens from the patient's perspective?**
2. **Shared Decision-Making Model**
   1. Expertise of Patient or Surrogate
   2. Expertise of Clinical Team
3. **Patient-Centered Goals of Care**

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Ethical Decision-Making

A. Ethical Frame
   1.) Facts
   2.) Values/Preferences/Beliefs
   3.) Professional Responsibilities
   4.) Ethical Principles
   5.) Courses of Action
   6.) Justification
   7.) Preventative Ethics

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Next Steps…….

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OurNotes

- Collaborative Electronic Health Record!
- What happens when providers and patients and families collaborate on the record???

Mafi, Walker, Delbanco, et al. Ann Intern Med. Published online November 14, 2017. doi:10.7326/M17-0583

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OpenNotes Resources

- Mental Health Tool Kit
- FAQ's
- Research Literature

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OpenNotes

Please visit the OpenNotes website for more information,
including research, videos, FAQs and toolkits.

www.opennotes.org

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