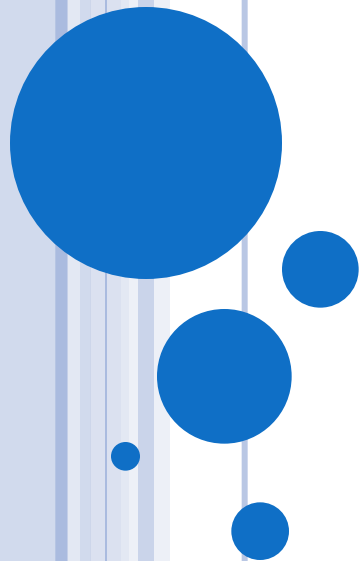


PRIVACY: TENSIONS AND CHALLENGES

Privacy?

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WHO AM I (RELEVANT TIDBITS)?

- Family psychologist invested in family-centered collaborative care
- Clinical psychologist who has worked on a psychiatric inpatient unit since college freshmen
- Administrator and educator/trainer invested in guiding trainees, faculty, and staff in complex ethical decision-making and creative problem-solving that takes into account relevant laws/regulations/ethics codes, multiple/diverse needs of the patient/consumer, individual's caregiving system and relationship to them, and community/society





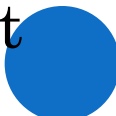
WHAT ARE THE PRIVACY LAWS?

HIPAA

- Health Insurance Portability and Accountability Act of 1996
 - Title I: Health Care Access, Portability, and Renewability
 - protects health insurance coverage for workers and their families when they change or lose their jobs
 - Title II: Preventing Health Care Fraud and Abuse; Administrative Simplification; Medical Liability Reform –
 - requires the establishment of national standards for electronic health care transactions and national identifiers for providers, health insurance plans, and employers
 - includes the Privacy Rule, which regulates the use and disclosure of Protected Health Information (PHI) by covered entities



HIPAA PRIVACY RULE GOALS

- Recognize that at the end of the day, it is the patient's/consumer's privacy, not the provider's privacy
 - Ensure privacy of individual health information, without interfering with access to treatment, health care operations, or quality of care
 - Enhance patient/consumer-centered care
 - Enable patients/consumers greater access and control over their medical records
 - Individual Choice Principle grants individuals the opportunity to set limits on the uses and disclosures of their health information
 - Establish continuity in rules governing management of PHI
- 

HIPAA PRIVACY RULE BACKGROUND

- Federal *floor* for privacy protection
- Four basic entities are subject to PHI
 - Health care providers
 - Insurers
 - Health claims clearing houses
 - Business associates and their subcontractors
- Diagnosis, medications, and dates and types of service are available for disclosure to these entities without patient/consumer consent, but state mental health privacy laws typically require consent
- But because more privacy-protective state laws are not preempted by the HIPAA Privacy Rule, at least consent is required for the release of most mental health PHI



HIPAA PRIVACY RULE BACKGROUND

- Patients/consumers must be notified about their privacy rights and be clearly informed about how PHI will be used
- Patients/consumers can request limitations to sharing PHI but an organization is not required to honor this request
 - But under Omnibus Rule, people can insist that PHI related to care paid for out-of-pocket be withheld from health insurers
 - Mental health information could be included within medical record, unless it is kept separate as part of “psychotherapy notes”



HIPAA PRIVACY RULE – 2013 CHANGES

- 2013 Changes – Released 1/13, Effective 3/13, Compliance required by 9/13
- Referred to as Omnibus Rule or Final Rule
- Added more privacy and rights
- Long term protection of PHI was changed from indefinite to 50 years



HIPAA PRIVACY RULE – 2013 CHANGES

- Updated Privacy Notices must include the following if relevant:
 - Uses and disclosures of psychotherapy notes
 - Uses and disclosures of PHI for marketing purposes
 - Disclosures that constitute a sale of PHI require patient/consumer authorization
 - Patient/consumer can restrict certain PHI disclosures to health plans/insurance companies if patient/consumer pays out of pocket in full
- Business associates and their subcontractors generally must comply in the same way as covered entities



HIPAA PRIVACY RULE – 2013 CHANGES

○ Breach Notification Rule

- “Impermissible use or disclosure” of PHI is presumed to be a breach in some cases and affected patients/consumers have the right to be notified
- Unless a risk assessment demonstrates a low probability that PHI has been compromised. Factors:
 - Nature and extent of PHI involved
 - To whom PHI may have been disclosed
 - Whether PHI was actually acquired or viewed
 - Extent to which risk to PHI has been mitigated

○ More severe financial penalty structure for violations

- Fines range from \$100-\$50,000/violation, with a cap of \$1.5 million if make same mistake more than once a calendar year (when don't appear to be trying to comply)



HIPAA - COMMUNICATION WITH CAREGIVERS

- A covered entity may rely on an individual's informal permission to disclose information to family members and caregivers
- Hospitals may inform caregivers that a person is there/general condition, etc, as long as patient/consumer is informed and agrees
- Several states permit disclosures to family members and caregivers



HIPAA – LACK OF CAPACITY TO CONSENT

- If an emergency exists and/or the person lacks the capacity to agree/object, a provider may provide health information to caregivers if it is in the individual's best interest based on the provider's judgment
- A designated surrogate should be vested with authority to make decisions in cases of incapacity (rule is not clear if formal determination of incapacity is necessary)



HIPAA – COMMUNICATING INFORMATION TO PROVIDERS

- Covered entities can accept information from family members/caregivers knowledgeable about the individual and his/her behavioral health status and treatment history and needs



FERPA

- Family Educational Rights and Privacy Act (FERPA)
 - Gives parents and students the right to access student records; prevents unauthorized 3rd party access
 - Prohibits release of records without consent
 - Applies to all public or private educational agencies that receive federal educational funding
- Records can include information on treatment of substance use disorders or mental illness
- Records covered by FERPA are not subject to HIPAA (boundary between the two is complex); FERPA, in effect, adds an extra layer to federal law governing health information
- HIPAA does not apply to student records created on campus



FERPA

- Allows for communication about a specific student among institution of higher education (IHE) staff, faculty, and administrators who are concerned about the welfare of the student or the community
- Recognizes that IHEs have an independent duty to notify parents, health authorities, or law enforcement of a student's dangerous, suicidal, and/or self-destructive behavior if sharing such information is in an effort to protect the health or safety of the student or other individuals if there has been a determination that there is an articulable and significant threat and that the situation is an emergency





WHAT IS THE MAIN CHALLENGE?



BIG CHALLENGE

○ Balance:

- Obtaining a more comprehensive picture of patient's/consumer's status and needs and engaging other key people in the patient's/consumer's life (e.g., health care providers, family/friends/community members) in understanding and caring for the patient and protecting the public
- Protecting the patient's/consumer's privacy and developing/maintaining a trusting relationship with the patient/consumer



BIG CHALLENGE

- Comprehensive, Collaborative, and Family-Centered Care
 - Acknowledges that collaboration with other health-care providers and caregivers is best to address complex issues
 - Allows for the ability to streamline and coordinate across providers and other disciplines, which can increase the efficiency of treatment
 - Recognizes that involving family members and caregivers can yield valuable information, improve treatment adherence especially for people with behavioral health problems, and offer these people much needed support
 - Protects providers from negligence claims



BIG CHALLENGE

○ Protection Side

- Ensures freedom from unwanted intrusions into one's life
- Acknowledges that the potential effects of unauthorized disclosure include social stigma, employment discrimination, insurance discrimination
- Recognizes that the potential effects of addiction disclosure can cause criminal prosecution, employment termination, forfeiture of legal protections, or right to receive disability benefits
- Understands that fear of disclosure can create a disincentive for seeking treatment and negatively affect the provider-patient/consumer relationship



BALANCING CHALLENGES: HOT TOPICS

- Interdisciplinary Collaboration
- Electronic Health Records
- Record Keeping
- Family Involvement
- Mental Health Disclosure Related to Firearms





INTERDISCIPLINARY COLLABORATION:

**A CERTAIN DEGREE OF SHARING
FACILITATES CARE COORDINATION,
BUT TOO MUCH MAY THREATEN
PATIENTS'/CONSUMERS' PRIVACY
RIGHTS**

INTERDISCIPLINARY COLLABORATION: SHARING

- Supports a one-stop holistic approach versus separate evaluations and interpretations
 - Patient/consumer, interdisciplinary health care team, and family together can develop a comprehensive assessment and create and implement action plans
- Values a “team-patient/consumer” rather than “doctor-patient/consumer” relationship for comprehensive and effective diagnosis and treatment
- Supports collaboration not only within system but across systems (e.g., health care, school, law enforcement)



INTERDISCIPLINARY COLLABORATION: SHARING

- Ensure that all concerned parties are on the same page, have the same information, and are working together for the good of the individual and the community
- Affords professionals the opportunity to learn from each other



INTERDISCIPLINARY COLLABORATION: PRIVACY

- Keeps information confidential unless such disclosure is needed for providing necessary services or protecting the individual or others from harm
- Emphasizes that health care experiences focus on patients'/consumers' preferences, not health care providers' or family members' preferences
- Ensures health care providers' adherence to relevant regulations with regard to patient/consumer autonomy (e.g., HIPAA, FERPA) and to ethics codes with regard to confidentiality and disclosure





ELECTRONIC HEALTH RECORDS (EHRs):

**IMPROVEMENTS IN SAFETY,
QUALITY, AND CARE EFFICIENCY BUT
DRAWBACKS IN ABILITY TO CONTAIN
AND SAFEGUARD INFORMATION**

EHRs: SHARING

- Allows for greater patient participation (e.g., patient can enter medical, psychological, social information into EHR)
- Improves efficiency, decreases medical errors, and increases access to patients' records for concerned providers
- Improves collaboration between behavioral health and health care providers
 - Behavioral health providers can gain access to information about pertinent medical problems/diagnoses and medications
 - Health care providers can utilize information about behavioral health diagnoses and treatments to inform their health-care understanding and decision-making



EHRs: PRIVACY

- Increases likelihood that non-behavioral health care provider could misinterpret a person's behavioral health status or stigmatize people with behavioral health diagnoses and treatment (opposite could be true)
- Risks of internet security breaches, thus making behavioral health notes potentially public unless they were blocked to other health care personnel





**RECORD KEEPING:
THOROUGHNESS AND PROTECTING
THE PROVIDER VERSUS PROTECTING
CONFIDENTIAL INFORMATION**

RECORD KEEPING: DETAILED

- Allows for better continuity of care due to increased communication among providers
- Ensure that health care professional has adequate and credible information to share if treatment called into question
- Protects the health care professional and agency, particularly from potential claims of negligence or licensing board complaints



RECORD KEEPING: LIMITED

- Enables providers to protect people's confidentiality and remain HIPAA compliant
 - Document dates of service, type of treatment, and diagnosis
 - Keep in secure file in provider's office additional information the patient/consumer does not want in the record shared with others in healthcare system (of course records can still be used during litigation)
- Requires specific consent for disclosure of psychotherapy notes
- Underscores importance of safeguarding data – use all means necessary to protect information





**FAMILY INVOLVEMENT:
ENHANCING SUPPORT THAT MIGHT
LEAD TO A QUICKER RECOVERY
VERSUS AUTONOMY AND THE RIGHT
TO BE FREE FROM TREATMENT
INTERFERENCE**



the Atlantic

DECEMBER 26, 2012

**FAMILIES MUST BE OUR FIRST
RESPONDERS**

FAMILY INVOLVEMENT: ENGAGEMENT

- Provides families/caregivers with access to essential information and ensures that families of individuals with mental illness are not denied access to basic information
- Recognizes that family support is often linked to better outcomes, especially when there are agreements about family members' roles, when their strengths are tapped into, and when they are provided with the necessary tools to effectively assist their loved one
- Offers an “early-warning system” and “first line of defense” that can be helpful to the patient/consumer, health care provider team, and community



FAMILY INVOLVEMENT: ENGAGEMENT

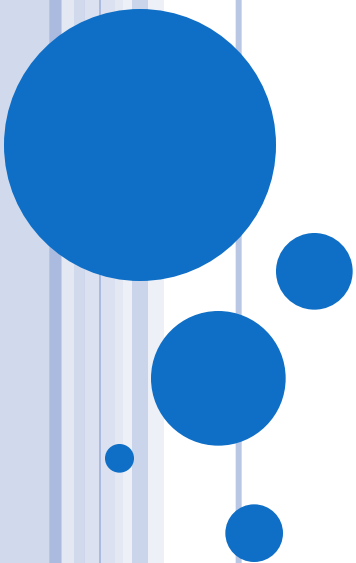
- Provides a support network that can encourage the patient/consumer to seek and avail him/her self of much needed treatment
- Affords individuals with serious and persistent mental illness assistance in self-management in the community (e.g., emotional support, diet, activities, relationships)



FAMILY INVOLVEMENT: ENGAGEMENT

- Offers the care provider the opportunity to address and help relieve family members' concerns
- Acknowledges that the bidirectional sharing of information typically is positive and helpful
- Increases the likelihood that a mental health advance directive is in place such that the individual with behavioral health problems can provide a written document of his/her treatment desires that loved ones can follow if he/she becomes too incapacitated by his/her mental illness to make good decision





THE WALL STREET JOURNAL

JUNE 7, 2013

**FAMILIES OF VIOLENT
PATIENTS: 'WE'RE LOCKED OUT'
OF CARE**

FAMILY INVOLVEMENT: PRIVACY

- Ensures consistency with HIPAA limitations
 - Covered entity can rely on a patient's/consumer's informal permission to disclose to a family member, but people can restrict disclosure to notify family members unless it is an emergency situation or the person lacks capacity and the provider deems it to be in the patient's/consumer's best interests based on professional judgment
- Acknowledges a patient/consumer may not want family members to be involved for a variety of reasons, some of which reflect the person's difficulties (e.g., paranoia, avoidance of difficult conversations) and others that may reflect family dynamics (intrusiveness, dysfunctional relationships, family not always having patient's/consumer's best interest in mind)



FIREARMS: PUBLIC SAFETY GOALS VERSUS INDIVIDUAL PRIVACY

THE WALL STREET JOURNAL

JUNE 13, 2013

**MEDICAL GROUPS PUSH BACK
AT GUN-LAW CHANGE**

FIREARMS: PUBLIC SAFETY

- Reporting - Recognizes that HIPAA and FERPA allow for disclosure without authorization to avert serious threat to health or safety (balance privacy interests with important safety goals) (i.e., in case of potential firearm use, family violence) in a manner that is consistent with the law
- Gun background checks - Attends to the HHS notice of proposed rulemaking with regard to providing mental health information into the national gun background check data base




FIREARMS: PRIVACY

○ Reporting –

- Acknowledges concerns that reporting may reduce trust and service utilization
- Recognizes that state laws may restrict disclosures beyond those restrictions enumerated by HIPAA

○ Gun background checks –

- Acknowledges concerns that reporting may reduce behavioral health care utilization and increase stigma
 - Recognizes concerns that reporting inappropriately reveals the behavioral health status of individuals, most of whom will be never be violent (current system only requires reporting if person has been adjudicated or involuntarily committed)
 - Reflects fears of legal repercussions by HIPAA-covered entities regarding submitting information to the National Instant Criminal Background Check (NICS) even though only name, demographics, and mental health prohibiter code are submitted to NICS
- 



**Take
home message*

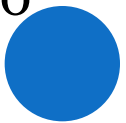
TAKE HOME MESSAGES

TAKE-HOME MESSAGES


- Decision-making must occur in the context of the relevant regulations, state and federal laws, and ethics codes, as well as the setting
- There is a constant tension between
 - Privacy and collaboration
 - Privacy and engagement
 - Privacy and the safety of the individual, the provider, and the public
- Most complex cases are gray, which is why there are such different views
- We must find ways to reconcile privacy and quality care



TAKE-HOME MESSAGES

- Policies need to be collaboratively created by administrators across types of systems, providers across systems, consumers, and family members related to the sharing of information
 - Educational programming needs to address the complexities of decision-making with regard to privacy/sharing and the ways in which to engage consumers, families, and other systems in appropriate and helpful information sharing
 - Debriefings should be utilized to address challenges to information sharing after differences occur related to difficult situations (e.g., community violence)
- 

TAKE-HOME MESSAGES

- Social media is changing the privacy landscape (e.g., people sharing more through social media, which reduces stigma), highlighting the dynamic nature of these dilemmas
 - Payment reform associated with healthcare reform also is/will change the landscape (e.g., outcomes key as reflected in EHRs)
 - Our own histories, roles and responsibilities, and values and beliefs influence where we fall on each of the issues
 - Team work and creative problem-solving are needed to steer a well-balanced course
- 



QUESTIONS?

