Balancing digital information-sharing and patient privacy when engaging families in the intensive care unit

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ABSTRACT

Patients in intensive care units (ICUs) may lack decisional capacity and may depend on proxy decision makers (PDMs) to make medical decisions on their behalf. High-quality information-sharing with PDMs, including through such means as health information technology, could improve communication and decision making and could potentially minimize the psychological consequences of an ICU stay for both patients and their family members. However, alongside these anticipated benefits of information-sharing are risks of unwanted disclosure of sensitive information. Approaches to identifying the optimal balance between access to digital health information to facilitate engagement and protecting patient privacy are urgently needed. We identified eight themes that should be considered in balancing health information access and patient privacy: 1) potential benefits to patients from PDM data access; 2) potential harms to patients from such access; 3) the moral status of families within the patient-clinician relationship; 4) the scope of relevant information provided to PDMs; 5) issues around defining PDMs’ authority; 6) methods for eliciting and documenting patient preferences about their family’s information access; 7) the relevance of methods for ascertaining the identity of PDMs; and 8) the obligations of hospitals to prevent privacy breaches by PDMs. We conclude that PDMs should typically have access to health information from the current episode of care when the patient is decisionally impaired, unless the patient has previously expressed a clear preference that PDMs not have such access.

Keywords: access, digital information, ethics, intensive care unit, patient-centered care, patient engagement, patient privacy, personal health records, shared decision making

INTRODUCTION

Case 1: J, a 62-year-old man with diabetes and obesity, is admitted with pneumonia that progresses rapidly to respiratory failure, requiring mechanical ventilation in the Intensive Care Unit (ICU). An intern tells J’s family that the team is checking a brain computed tomography scan to see “whether he [J] has brain damage.” The intern tells the overnight intern to follow up on the scan, but forgets to ask his colleague to communicate with J’s daughter (S), who remains watchfully at J’s bedside. S spends the entire night fearing that no news is bad news. Although J ultimately recovers, S develops symptoms of post-traumatic stress disorder, which may be related, in part, to the lack of access to J’s health information during his ICU stay.

Case 2: M, the 68-year-old matriarch of a large Catholic family, is admitted to the ICU after cholecystitis complicated by septic shock and respiratory failure. She is on a ventilator for 2 days. During that time, her husband, acting as her proxy decision maker (PDM), was granted access to her medical record and discovers an old gynecology note about M having undergone a therapeutic abortion. No one in the family had known about the abortion. M recovers to find that a firestorm of controversy has arisen within her family.

These hypothetical cases offer extreme examples of how and when healthcare institutions might share ICU patients’ digital health information with PDMs. On the one hand is an example of family members being excluded from access to a patient’s relevant health information. (As in our prior work, we use the term “family” to refer to those members of patients’ intimate social networks who are involved in their care.) On the other hand is an example of the risk of inadvertently disclosing private patient information to PDMs when they are given access to the patient’s health information. This paper describes the ethical considerations involved in making health information available to the PDMs for ICU patients. Herein, we consider a variety of means of making elements of a patient’s medical record available to both patients and their designers, including electronic portals.

There are differing terminologies defining PDMs in legal, medical, and social contexts. “Personal representatives,” “surrogates,” “proxy,” and “substitutes” all have distinct regulatory denotations and ethical connotations. In this paper, we use the common clinical meaning of “proxy” as a general category of people who make decisions for another person (the patient) rather than the term’s technical legal sense of a personal representative appointed by the patient (unless distinct use of a particular term is specifically noted).

Although ICUs have achieved astounding success at treating once-fatal diseases,2 the burdens of ICU treatment remain substantial.3–5 Over half of patients and families of patients admitted to the ICU will develop Post-Intensive Care Syndrome (PICS).6 While adapting to the challenges of post-discharge care7 or bereavement,8 families often struggle with the emotional sequelae of their ICU experience, described in the literature as “PICS-Family.”6,9–13

Families play essential roles during ICU admissions. Because most ICU patients are not fully aware of their surroundings/situation, proxy decision making is common in ICUs.14,15 Families also provide care during and after the ICU stay.16 Helping out in these ways may contribute to “facilitated sense making,” by which clinicians assist...
families in making sense of the potential tragedy of the patient’s life-threatening illness. 17,18 Families may also assume a safety advocate role, participating in efforts to avoid preventable harm to the patient. 19

However, ICUs have historically been clinician-centered, arranged for the convenience of physicians and nurses rather than patients and families. Some pioneers have begun to model patient-centered20 alternatives. Patient-centered care depends on patient and family engagement (PFE) in full partnership with clinicians,19,21,22 especially through shared decision making.1,23 Encouraging PFE and shared decision making, including the use of decision-support systems, requires timely, reliable information transfer between clinicians and patients/families.25,26

To become more patient-centered, improve communication, and facilitate PFE, various methods have been developed to give patients access to clinical documentation,18,29 including the OpenNotes initiative.27 Although early results on the efficacy of these methods were mixed, data increasingly support these mechanisms as ways of improving patient-centered care delivery, the effectiveness of health services, and health outcomes.28 Patient portals that facilitate access to patient health information were initially designed for use in outpatient settings by competent patients, who were given direct control over access.29,30 These portals offer advantages, but there are ongoing privacy concerns when personal information is stored electronically. Although most individuals are comfortable sharing standard health information with family members, certain classes of information (eg, mental health status, reproductive history, sexual history, or diagnoses of stigmatized diseases like human immunodeficiency virus) may be sensitive.31 Data security breaches are distressingly common, so increased electronic access to health information may be viewed with concern.32 Extension of electronic access to patient health information to inpatient or critical care environments is nascent but likely to increase.

In the current ICU milieu, families report feeling starved for information.18,33 Information-sharing typically occurs face-to-face and is piecemeal, without clear guidance for clinicians on how and when to divulge what pieces of information.

APPROACH

The Privacy, Access, and Engagement Task Force of the Libretto Consortium was convened to address regulatory barriers to PFE in ICUs and clarify the tradeoffs between health information access and patient privacy. To meet these goals, we included representatives of a patient foundation and a Patient Family Advisory Council34 as well as specialists in critical care, health law and privacy, health services research, lay advisor management, medical ethics, patient-centered care, patient experience, psychology, shared decision making, and social work. The Libretto Consortium, supported by the Gordon and Betty Moore Foundation, aims to fundamentally reengineer ICUs, with an emphasis on systems engineering and preserving respect and dignity for patients and their families.35,36

We used an interactive process, exploring ethical concerns and research priorities, to develop this paper, which included holding an in-person meeting in February 2015 as well as exchanging iterative drafts over e-mail and supported by telephone conferences. Themes and potential topics were identified and discussed among authors to saturation, with elimination of redundant or non-central themes. We discussed our preliminary findings at an in-person meeting of the entire Libretto Consortium in Chicago in May 2015. We will separately report the results of a parallel review of relevant federal and state laws.

SUMMARY

Eight distinct themes emerged from the Task Force’s discussions: 1) potential benefits to patients from family data access; 2) potential harms to patients from such access; 3) the moral status of families within the patient-clinician relationship; 4) the scope of relevant information provided to PDMs; 5) issues around defining the authority of PDMs; 6) methods for eliciting and documenting patient preferences about their family’s information access; 7) the relevance of methods for ascertaining the identity of PDMs; and 8) the obligations of hospitals to prevent privacy breaches by PDMs. Table 1 displays important ethical considerations.

Potential Benefits to Patients from Family Data Access

Most ICU patients lack decisional capacity at some point during their ICU stay. Most patients want their families to exercise full medical decision-making authority on their behalf,37 and proxy decision making relies on adequate information exchange between clinicians and PDMs. Providing PDMs access to the medical records of incapacitated patients could ameliorate knowledge asymmetries and improve shared decision making.38

Patient safety may be improved by improved information sharing, although systematic data to support this theory are sparse. For example, more informed families might notice medication errors or ask questions that fine-tune clinicians’ thinking. If experience with PFE in other arenas extends to ICUs, better communication and information-sharing may also reduce the costs of unwanted or unnecessary care.28 Greater information-sharing between clinicians and families could also enhance respect and dignity for both patients and their families in the ICU.39,40 In qualitative research, patients and their family members specifically identified information-sharing as an important component of being treated with respect and having confidence in their clinicians.41

Family members frequently transition to caregiving roles after a patient is discharged from the ICU,16 assuming substantial direct care responsibilities for the patient. Family caregivers may provide continuity that may otherwise be absent in patients’ transitions to other care settings. Improving PDMs’ understanding about diagnoses and changes in the patient’s condition may also help families adopt more informed caregiver roles or better navigate bereavement.

In addition, the ICU diary, in which nurses and families co-create a lasting narrative of an individual’s ICU admission that can replace a patient’s possibly delusional memories of their stay, is one of the few interventions shown to decrease symptoms of PICS among ICU survivors.42,43 As logs of events during the ICU stay, these diaries require ongoing, effective information-sharing.

Although broader dissemination of health information beyond PDMs complicates assessing the risks and benefits of information access, some patients may value easy methods for keeping members of their larger social networks apprised of their status.44 The popularity of services such as CaringBridge suggest the value of such opportunities.45

Potential Harms to Patients from Family Data Access

Unplanned and/or undesired disclosures of patient health information are the primary risks of family access to such information. Such disclosures could include information about mental health, substance abuse, reproductive history, sexual behaviors, and sexually transmitted infections, among other types of information.31 The case of M presented at the beginning of this paper exemplifies such risks.

In addition, unless workflow is carefully managed, technology might inadvertently cause clinicians to decrease the amount of face-to-face communication they have with patients and families. This was noted to be a significant concern in focus groups with clinicians (Sigall Bell, MD, personal communication). Unmediated access to health
information could increase the risk of families misunderstanding that information, especially when technical details are inadequately contextualized or explained without an in-person discussion with the clinician. For example, families may understandably interpret a patient’s decreased serum creatinine during continuous renal replacement therapy to mean true clinical improvement, when, in fact, it does not indicate such improvement. Such misunderstandings could contribute to families’ distress, although the rollout of OpenNotes has not borne this out in the outpatient arena.\(^{46}\)

Relatedly, default information transfer approaches within given systems may not be useful to many patients/families.\(^{28}\) One problem is “information dump.” For example, radiology reports that list theoretically possible, but generally unlikely, diagnoses might induce anxiety when read by a patient or family member.\(^{47–49}\) Curation of health information or requirements for clinicians to approve information transfers may mitigate risks but impose substantial new burdens on busy clinicians. However, in refutation of concerns about information overload, some studies have reported that, when they are asked, patients and families want as much information as they can get.\(^{24,50–52}\)

The Moral Status of Families Within the Patient-Clinician Relationship
In adult medicine, the privileged, fiduciary relationship between clinician and patient has traditionally not extended to the relationship between clinicians and families. However, this model has been changing recently, in complex ways. In obstetrics, attention has been drawn to the father/partner as a “second patient” during childbirth.\(^{53–55}\) In palliative care, clinicians are increasingly understood to have obligations to families.\(^{56–58}\) In ICUs, families are increasingly considered to be central members of the care team.\(^{24}\)

Tradeoffs between the needs of patients and families have sometimes been framed in terms of whether a patient’s desire for additional treatments may impose excessive burdens on families.\(^{59,60}\) Independent of controversial proposals, such as that burdens on families may generate a “duty to die,”\(^{61,62}\) lesser tradeoffs between patient and family needs may be morally required. If limiting access to a patient’s health information causes psychological distress for a family member or makes informal caregiving more burdensome—say, by failure to communicate a laboratory value that affects patient care, clinicians are increasingly understood to have obligations to families.\(^{56–58}\) In ICUs, families are increasingly considered to be central members of the care team.\(^{24}\)

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Moreover, families’ and patients’ interests in information access may align. Patients may be interested in preventing family members from suffering psychological distress associated with inadequate information access. Such interests might extend to family members’ grief being complicated by inadequate communication and information transfer between clinicians and families while the patient was alive. Unfortunately, clinicians generally do not know which patients will live at the time decisions must be made in the ICU.\(^{63}\) so ways of maintaining the balance of information access and privacy cannot depend on knowing beforehand that the patient will certainly die.
The Scope of Relevant Information
Data “segmentation” — arranging data to allow for separate management of certain kinds of information, such as mental health records — is difficult, expensive, and error-prone, but represents a basic reality that not all health information is equally sensitive or important for ICU patients’ families to know. The more relevant particular information is to proxy decision making and caregiving, the more important it is to maximize PDMs’ access to it. The Health Insurance Portability and Accountability Act (HIPAA) explicitly states that patient authorization is not necessary for disclosures of relevant information to individuals involved in the patient’s care, whether or not they are legally recognized as PDMs, as long as patients have the opportunity to object if they are able. Although laws may not be ethically sound, we mention HIPAA because, anecdotally, this law is erroneously invoked to bar information-sharing and permits states to restrict information transfer further — see 45 CFR § 160.203(b) (2014) — which runs counter to the need for information-sharing in the ICU setting. However, the ethical mandate for information-sharing with PDMs is clearest when it relates to the current medical encounter. Health information that is unrelated to the patient’s ICU stay has little claim to an ethical necessity for sharing.

Defining the Scope of Proxy Decision Making
Documents such as a durable power of attorney for healthcare may explicitly designate a PDM for a patient. In the absence of such documents, most states apply default priority scales to identify PDMs. Historically stigmatized relationships may not be included in some statutory priority scales, although many states (eg, Alaska, Arizona, Colorado, New York, and Pennsylvania) now include knowledgeable close friends who have exhibited special care and concern in the default scale, albeit with lower priority than legally recognized family members. Under HIPAA, individuals legally recognized as decision makers have the same rights as patients to access a patient’s medical information, unless patients have specified otherwise or state law limits these rights.

Local care environments may be more or less inclusive than federal or state legislation requires, and there are distinctions between de jure and de facto identification of PDMs. In our collective experience, clinicians tend to informally apply statutory requirements, seeking the most relevant individual in the moment rather than following formal legal guidelines. Intrafamily conflicts and, possibly, competing interests between family members and the patient can further confound the determination of information access for PDMs.

Identification of Individual Preferences Regarding Privacy
When patients are unable to communicate their desires in regards to allowing PDMs to have access to their medical information, alternative methods must be used to determine their preferences. In surveys, about 80% of patients using the Veterans Affairs personal health record wanted family members to have access to the record, 64 patients who shared their OpenNotes with others had no increased concerns about privacy vs those who did not, and about a third of the patients overall were worried about privacy. 65 These results indicate that the large majority of patients prefer that their family have access to their medical information, but they also underscore the fact that a minority of patients do not want their information shared with others. When individuals have made their preferences regarding information access clear, those preferences should be honored to the extent possible. Ideally, this should be managed through the designation of a healthcare proxy in advance of any serious medical crisis. Many state statutes (eg, Idaho, Illinois, Minnesota, and North Carolina) now invite patients to stipulate any limits on their decision maker’s access to their medical information. When a patient’s advance planning documents are unavailable, it seems appropriate to determine these preferences in the same way as other decisionally relevant preferences — through discussion with the patient’s family. We acknowledge that there may be a conflict between family members’ desire for information and their obligation to represent the patient’s values, but we anticipate that such conflicts are rare.

Verifying Identity of Individuals Receiving Access
Assuming that patients are willing to share their medical information with PDMs, what is the appropriate standard for verifying (“proofing”) the identity and authority of PDMs? The current practice for verifying PDM identity and authority is largely intuitive, with bedside clinicians determining when extra steps are required to confirm PDM identity or authority. Unfortunately, implicit biases or inadequate training, eg, related to racial or sociocultural differences, which may affect multiple aspects of medical care, 66–69 could lead to differences in patients’ and families’ access to health information. 70

The process of identity proofing and authentication requires careful thought and planning. Whatever techniques are developed to accomplish this will need to take into consideration that standards such as requirements for photo identification or legal address may differentially restrict data-sharing for certain groups. In addition to access, sociocultural sensitivity may require that records have different interfaces and different language options, depending on the needs of individual patients and/or families.

Processes that rely on publicly available information, such as addresses, birthdates, or parents’ names, are vulnerable to exploitation, as demonstrated by recent publicly reported data breaches. 32,71 Such situations have occurred in high-profile cases involving celebrities. 72 Regardless, whatever methods are used to verify PDM identity should not alienate the individuals whose identity is being verified. Also, the proofing processes should not impinge upon clinician workflow, which would distract clinicians from their work at the bedside of sick patients.

Obligations to Prevent Unauthorized Use of Information
One concern about sharing patients’ medical information access is that PDMs, unthinkingly or even deliberately contravening their responsibilities, may release information that patients consider private. For example, what if a patient’s surrogate were to accidentally post a patient’s log-in credentials to an open forum, such as a social media website or CaringBridge? 73 Of course, patients themselves may commit similar errors of judgment. In such a circumstance, what obligation does a healthcare system bear? A simple warning, together with a discussion about the reasons for it, may suffice to discharge this duty. Should PDMs or patients request the termination of an account, of course, such a request should be honored immediately.

CONCLUSIONS
We believe there are sufficient reasons to recommend that PDMs be granted access to patient health information that is relevant to the current episode of care. HIPAA’s standard for access for PDMs in the ICU permits such access, and the need to balance the benefits and risks related to such access should not lead states to be more restrictive about who can access patient health information.

Based on our review of the relevant ethical considerations regarding the sharing of patient health information with PDMs, we advocate the following practical approach for granting access to patient health information to family members. When patients are able to make decisions for themselves, they may grant such access at their discretion. When patient are decisionally impaired, unless they have explicitly restricted access, PDMs should receive access to the patient’s health information restricted to the current episode of care. Many information systems
already have this capability. We do not advocate approaches to the “segmentation” of data that are more onerous or complex than restricting access to the current episode of care. PDMs should be identified by a single process, whether for the purposes of clinical decision making, in-person daily updates, or access to a patient’s health information. There is no ethical reason for facilities to impose a more onerous system of PDM identification for securing access to patient information in the ICU than in other clinical decision making situations.

Further research on the ICU experience and the empirical outcomes of improving access to patient medical information for PDMs is indicated. Such research should investigate whether standards of PDM identification and authentication impose differential burdens; the efficiency and utility of different methods for identifying and recording patient preferences regarding PDM information access; as well as patient attributes that may then more likely express a desire to restrict access to their medical information. Stakeholder consultation regarding the tradeoffs between patient privacy and health information access may also be beneficial.

**CONTRIBUTORS**

S.M.B. drafted the manuscript. All authors made substantial contributions to the conception and design of the work. All authors revised the manuscript for important intellectual content. All authors provided final approval of the version of the manuscript to be published. All authors agree to be accountable for all aspects of the work.

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