Research and Applications

Preserving privacy for pediatric patients and families: use of confidential note types in pediatric ambulatory care

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ABSTRACT

Objective: This study evaluates and characterizes the use of a confidential clinic note type as part of the implementation of open notes at a free-standing children's hospital. We describe how this electronic health record feature which disables patient and family access to selected notes in the patient portal is used across our institution, which clinicians are using this feature, and the type of data our clinicians consider confidential.

Materials and Methods: Through retrospective chart review, we have evaluated the use of a confidential note type over a 1-year period.

Results: We identified 402 964 clinic notes created during a 1-year period, of which 9346 (2.3%) were flagged as confidential. Use of this confidential note type was associated with female patient sex and increase in patient age. It was used most frequently by a small subset of providers. 922 (83.8%) of 1100 notes manually reviewed contained sensitive information. Reasons for confidential notes varied, but patient's mental health was most commonly identified.

Discussion: Our data demonstrate variability in the use of a confidential note type across specialties, patient ages, and types of confidential information. This note type is frequently utilized by a subset of providers who often manage sensitive patient and parent information. As vendors and institutions enable open notes, thoughtful implementation and provider education surrounding the use of this confidential feature is needed.

Conclusion: A confidential clinic note feature is an integral aspect of pediatric open notes implementation. This feature supports protection of confidential information pertaining to our patients and their caregivers.

Key words: (MeSH terms): personal health record, electronic health record, patient data privacy, confidentiality, pediatrics

INTRODUCTION

Since 2010, the OpenNotes initiative has promoted increased transparency between patients and providers through online sharing of provider notes with patients and families. Today, more than 40 million patients in the US can access visit notes online through a patient portal.¹ Sharing clinic notes is associated with improved patient understanding and empowerment, strengthened patient–physician relationships, and increased healthcare quality and safety.^{2–7} While open notes are beneficial, unique ethical, legal, and technical chal-

lenges arise when implementing them in the pediatric and adolescent setting.⁸ For these populations, healthcare organizations must consider multiuser or shared access to visit notes within the online portal, since 1 or both parents may have access to a note in addition to the adolescent. If all clinic notes are made available within an online portal with multiuser access, information contained within notes could compromise the privacy of the patient or parent. For example, an adolescent patient may confide in their doctor issues regarding their mental health or reproductive health. Likewise, a parent may

express concerns regarding intimate partner violence during their child's wellness visit. This information may need to be withheld from another parent with portal access to ensure safety. In addition, a provider may want to withhold a note from the patient portal due to documentation of significant disagreements between the provider and the patient/family over a diagnosis or treatment plan or concerns related to medical child abuse in order to preserve a therapeutic relationship with a patient and family.⁸

Recognizing some of these difficult situations, the American Academy of Pediatrics and the Society for Adolescent Health and Medicine recommend implementation of patient portals with thoughtful confidentiality standards, including the ability to classify notes as confidential, thereby disabling online access to selected clinical documentation.⁹ Despite clear recommendations, hospital policies and electronic health record (EHR) vendors demonstrate little consensus on how to operationalize these recommendations.¹⁰ Adding to the complexity, US privacy laws surrounding adolescent and parent medical record access vary by state, and many EHRs are not tailored to pediatric institutions.¹¹ Furthermore, standardizing this process is difficult, as providers have varied opinions regarding which clinic notes should be considered confidential.¹² Given the complex nature of multiuser portal accounts, some institutions entirely disable portal access to an adolescent patient's account, while others require an adolescent consent to share portal access with his or her parents, placing the adolescent in a dilemma of requiring them to explain to parents why they no longer have access to the portal. Other institutions permit both patients and caregivers access to visit notes but systematically disable specific clinic notes that are most likely to contain sensitive information (ie, gynecology, behavioral health, and adolescent clinics).¹³

Patients and parents at our freestanding pediatric institution may access clinic notes in the patient portal. Prior to the age of 13, ambulatory visit notes are available to the parent, but from the age of 13 up to 17, both the parent and adolescent patient can have access. Once the patient turns 18, parental access is withdrawn and only re-instituted in specific situations (eg, dependent adults). Additionally, at our institution, providers can denote specific ambulatory visit notes as confidential, thereby disabling portal access to these selected notes for patients and parents. Enabling a feature to flag and protect confidential information is a crucial step toward providing our pediatric patients and their parents access to their clinic notes while preserving their privacy, but there have been limited studies that examine how this feature is used by clinicians. Ideally, these elective 'confidential' notes are used as intended, but some providers may also use this feature without a discernible reason, thereby unnecessarily limiting the value of patient portal note access. In order to better understand the use of confidential note types in our pediatric ambulatory setting, we examined how the note type was being used, which clinicians were using the note types, and what types of information clinicians considered confidential and in need of privacy protection.

OBJECTIVE

This study evaluates and characterizes the use of a confidential clinic note type as part of the implementation of open notes at a freestanding children's hospital. We describe how this EHR feature which disables patient and family access to selected notes in the patient portal is used across our institution, which clinicians are using this feature, and the type of data our clinicians consider confidential.

MATERIALS AND METHODS

This study is a single-center retrospective chart review of ambulatory visit notes at our freestanding pediatric institution. We queried our enterprise data warehouse for all clinic notes generated during a 1-year period, June 1, 2016–May 31, 2017, for patients < 18 years, excluding notes generated from the 5 clinics that consider all notes 'confidential' (ie, adolescent, gynecology, psychiatry, substance abuse clinic, child protection team). Notes were separated by confidentiality status (ie, flagged as confidential or standard), associated clinic, patient age, provider type (ie, attending physician, house staff, advanced practice provider [APP, physician assistant, or nurse practitioner], or psychologist), and patient sex. Individual provider's use of confidential notes was also documented. Chi-square analysis was used to calculate association of patient sex with confidential note type. Simple linear regression was used to calculate association of patient age with confidential note type.

Using a random number generator, we selected a sample of notes (1100, 12%) which we randomly distributed among our team of physicians (CP, JH, FB) and manually reviewed. Our team identified and categorized confidential content within these clinic notes based on *a priori* categories. Types of confidential content included information related to a patient's or parent's mental health, substance abuse, sexual history/health, or involvement in violence or abuse. Additionally, narratives related to complex social situations (eg, divorce, intra-family arguments), situations requiring legal involvement, provider–patient/family disagreements, foster family/custody issues, medical child neglect, and misattributed paternity were also categorized as confidential content. When defining mental health, we included any Diagnostic and Statistical Manual of Mental Disorders (DSM-5) diagnosis, including depression, suicidal ideation, anxiety, autism spectrum disorder, and avoidant/restrictive food intake disorder (ARFID). We categorized psychiatric or substance abuse screening questions, such as the Patient Health Questionnaire-9 or the Home, Education and Employment, Activities, Drugs, Sexuality, and Suicide assessment, as confidential content regardless as to whether responses were positive or negative. As we identified this confidential content, we also inferred and denoted to whom a note's content should likely not be disclosed (ie, the parent/guardian, the patient, the parent/guardian and the patient, or another party).

These data were analyzed using descriptive statistics. Upon completion of initial chart review, 10% of the evaluated notes were re-reviewed by all reviewers, and Cohen's Kappa statistic was calculated to determine inter-rater reliability. This study was approved by our institutional review board (IRB-P00025845).

RESULTS

We identified 402 964 clinic notes that met our inclusion criteria during the study period. Of these, 9346 (2.3%) were electively categorized as confidential. The confidential note type was used across 33 clinics of 34 available clinics; providers in dermatology clinics did not designate any notes as confidential during the study period. A small number of clinics were identified as heavy users of this feature and accounted for 26% of all confidential notes: pain treatment clinic (40.2% of all their notes), headache clinic (23.5%), infectious disease clinic (8.7%), and developmental medicine clinic (6.6%) (Table 1).

From a provider perspective, the highest proportion of notes were denoted as confidential by psychologists functioning within multidisciplinary clinics (47.9% of their notes), although staff physi-

Table 1. Confidential Notes categorized by high-use clinics, provider type, patient sex, and patient age

	Manually Reviewed Confidential Notes (% of total reviewed notes)	Confidential Notes (% of total Confidential notes)	Total Notes
Total	1100	9346	402 964
High-Use Clinics			
Developmental Medicine	100 (9.1)	990 (10.6)	15 123
Headache	34 (3.1)	328 (3.5)	1398
Infectious Disease	40 (3.6)	158 (1.7)	1813
Pain Treatment	115 (10.5)	959 (10.3)	2384
Provider Type			
APP	91 (8.3)	609 (6.5)	53 385
House Staff	21 (1.9)	392 (4.2)	69 127
Psychologist	437 (39.7)	3215 (34.4)	6709
Staff Physician	551 (50.1)	5130 (54.9)	273 743
Patient Sex			
Female	611 (55.5)	5137 (55.0)	190 765
Male	489 (44.5)	4209 (45.0)	212 199
Patient Age			
< 13 years old	569 (51.7)	5199 (55.6)	293 424
13-< 18 years old	539 (48.3)	4653 (44.4)	109 540

Abbreviation: APP, advanced practice provider.

Figure 1. Percent of confidential notes created and categorized by patient age and patient sex.

cians (1.9%), APPs (1.1%), and house staff (0.6%) also used confidential notes. Three hundred thirteen providers (34.5% of 907 applicable note-signing providers during the study period) availed themselves of the confidential note type, with 10 providers accounting for 51.4% of its use. These 10 providers spanned 7 clinics and included staff physicians and psychologists. The confidential note type was significantly associated with the sex of patient, with clinicians more likely to flag a note as confidential if the patient was female (2.69% vs 1.98% of all notes for males, $P < .001$) and with increasing patient age ($OR = 1.09$, $P < .001$) (Figure 1). Notes for adolescents age 13–17 years old were more commonly denoted as confidential as compared to younger patients (4.2% for adolescents vs 1.8% for children < 13 years old).

Chart review

Chart review of our selected sample of 1100 notes (12% of the total 9346) that were flagged as confidential revealed that 922 (83.8%) contained discernable sensitive information (including negative screening questions). One hundred seventy-five (16.0%) had no discernable sensitive information, with 1 provider accounting for 110 (65%) of these notes. Weighted Cohen's Kappa statistic was calculated utilizing 110 (10%) of notes for 3 reviewers and was 0.92 ($P < .05$). Reasons for confidential notes varied (Figure 2).

Mental and behavioral health

The most commonly inferred reason for confidentiality included content related to a patient's mental or behavioral health (496 notes,

Figure 2. Type of confidential content for notes containing sensitive information (n = 922). Notes could contain content in more than 1 category.

53.8% of confidential notes reviewed containing sensitive information). In many of these notes, patients were described as dealing with mental health issues such as anxiety or depression and providers frequently documented that they met with patients and caregivers separately. Other notes described coping mechanisms for chronic pain or headaches, such as positive thinking or exercise, and described possible contributing psychological factors to these issues. Conversely, some of these visit notes included information related to home instructions and plan for behavioral diagnoses, such as ARFID, but did not contain any information which the patient or caregiver did not know.

Sensitive information regarding a parent's mental health was also commonly found within confidential notes (147 notes, 15.9% of total notes reviewed) and was most commonly referenced by mental health providers, but occasionally also by primary care clinicians and subspecialists. Some notes not only contained family past psychiatric history (sensitive information related to that family member) but also detailed guardian anxiety or mental health issues which were affecting the ability to assist in managing their child's chronic disease. Others contained general information about other family members' mental health.

Sexual health

One hundred fifteen notes (12.5% of total confidential notes reviewed) contained information related to the patient's sexual health. These notes included information regarding adolescents' sexual practices, contraception, sexually transmitted infections (STIs) or issues surrounding gender management/identity. Twenty-eight notes (2.5% of total notes reviewed) contained information related to a mother's STI diagnosis, most commonly in visit notes from the neonatal infectious disease clinic, where patients were being evaluated for a risk of perinatally acquired STIs such as human immune deficiency virus (HIV) and hepatitis C.

Other sensitive information

Additional reason notes that were tagged as confidential included documentation of physical and sexual abuse toward either patients (34, 3.1% of total notes reviewed) or a parent (16, 1.5%). Notes with documentation related to patients who were in the custody of social services, including information regarding biological parents, were also flagged as confidential (17, 1.5%). Some confidential notes described issues with the general social situation such as intra-family arguments or divorce (112, 10.2%), while others documented disagreements between the provider and the patient and/or caregiver (19, 1.7%)—most commonly seen when a patient or family seemed to disagree with a diagnosis or plan of care.

Confidential to whom?

Of the 922 notes containing sensitive information, 9 (1.0%) contained sensitive information likely hidden from the patient (eg, a mother's history of HIV or domestic violence only affecting a parent/guardian), 380 (41.2%) hidden from the parent/guardian (eg, an adolescent's sexual or substance use history), 192 (20.8%) from both the patient and parent/guardian, and 6 (0.63%) from other/not otherwise classified. In 325 notes (35.2%), reviewers were unable to determine to whom specifically the note was sensitive.

DISCUSSION

To our knowledge, this study provides 1 of the first evaluations of an EHR feature that allows healthcare providers to selectively denote individual clinic notes as confidential, restricting their release to the patient portal. Our data demonstrate that this feature is utilized across most ambulatory clinics and heavily utilized by a subset of providers who often manage sensitive patient and family information. Providers were significantly more likely to use the confidential note type for female patients and adolescents, particularly for older

adolescent girls, which likely reflects increased knowledge about and access to confidential care.¹⁴ Additionally, specific clinics, such as developmental medicine, infectious disease, or pain treatment/headache clinics were more likely to leverage this feature related to a variety of sensitive content that is routinely collected, including patient and parent reports regarding mental health, sexual health, substance use, and intimate partner violence.

This study emphasizes the complex nature of shared access to the patient portal. While prespecified sensitive laboratory testing and imaging study results can be withheld from the shared portal, disabling access to specific narrative note content is something that cannot be easily automated.¹⁵ Our findings suggest that narrative confidential content in clinic notes is nuanced—specifically in the pediatric setting where multiple caregivers may be present during a clinic visit in addition to the patient and may also have access to the notes through the patient portal. In our evaluation of confidential notes, our team found that for some of the visits, providers met with a patient and her parent(s) independently, emphasizing the sensitive nature of some of the conversations and the need for the availability of a confidential note type.

We also found that some notes designated as confidential did not appear to contain any identifiable sensitive information, which either reflected an error on the part of the provider or a reluctance to share any notes. In some cases, reviewers were unable to identify to whom a note may be confidential. Some of these cases were related to behavioral health DSM-5 diagnoses, such as ARFID or autism, where the parents and patient were clearly present for the entire visit; this category of notes contained visit information which could likely be helpful to a parent, such as a patient's diagnosis and detailed behavioral treatment plan. This highlights some ambiguity surrounding the sensitive nature of these types of diagnoses and the question as to whether they should be truly categorized as confidential simply because they are related to behavioral health. Prior data in the adult population suggest that patient access to these types of behavioral health notes may have a positive impact on a patient's treatment and improve patient understanding of their mental health condition.¹⁶

While this confidential note feature was more commonly used as patients aged, even notes pertaining to our youngest patients contained sensitive information. For example, a pediatric infectious disease clinic visit for an infant at risk for perinatally acquired HIV contained information that is truly confidential to the infant's mother; if unknown to other parties, the documentation of the mother's HIV status may pose a risk if later discovered by the infant's other parent or even later in life by the patient. This supports the concept that a confidential note option is important regardless of the age of the patient and may serve to protect information that is confidential to family members other than the patient.

Prior papers have demonstrated great benefit to patients and families with the use of open notes and described the need for thoughtful execution of multiuser pediatric portals with confidentiality standards, but none have detailed the use of a confidential note type.^{2–6,8,13,17} This study provides an example of an implementation of open notes which supports patient access to clinical documentation while simultaneously protecting the privacy of our patients and parents through an elective confidential note type. This study demonstrates that when this capability is implemented, it may be widely and appropriately used by a variety of providers.

The study has several limitations. This analysis was done at a single, large children's hospital institution which limits generaliz-

ability. Review of note content was subjective and reviewers retrospectively categorized note content apart from the context of an in-person clinic, perhaps leading to miscategorization of the confidential content or the intent behind classifying the note as confidential. We did not manually review any notes which were *not* categorized as confidential and therefore exposed in the patient portal, highlighting that we know little regarding any confidential content which may have been inappropriately shared in the portal.

CONCLUSION

A confidential note type can be successfully leveraged to preserve the privacy of pediatric patients and their families, while providing the benefits of open notes. This EHR feature was most commonly used when documenting visits for female patients and as patients age through adolescence. Confidential notes contained a variety of sensitive content, but most commonly contained information related to a patients' behavioral and mental health. EHR vendors should include documentation features to suppress confidential information from patient portals to support clinician needs and patient privacy.

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AUTHOR CONTRIBUTIONS

CP conceptualized and designed the study, designed the data collection instruments, collected data, carried out the initial analyses, and drafted the initial manuscript. FB and JH conceptualized and designed the study and collected data. All authors reviewed and revised the manuscript, approved the final manuscript, as submitted, and agree to be accountable for all content.

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CONFLICT OF INTEREST STATEMENT

None declared.

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