The Variation in Patient Portal Access for Adolescents in the United States: How Different Medical Centers Manage their Adolescent Access

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Introduction

Adolescence is a time when patients are approaching autonomy, both developmentally and legally. Yet they are still minors and are likely to encounter contradictions between situations in which they are treated as children and ones in which they are treated as adults. Being able to access their medical information may enable adolescents to take on a participatory role in their health care.[1] However, federal policy, state law, and community norms are not consistent regarding adolescent healthcare and privacy. For example, in some regions and under some circumstances, adolescents may have consent and privacy rights similar to those of adults, with the right to make some, or all, of their own sensitive medical decisions privately. In other cases, parental notification is the norm, or guidance is unclear or lacking.[2] In the absence of national guidelines, medical centers encounter serious challenges when developing policies about adolescent access to medical records via patient portals. The American Academy of Pediatrics has made recommendations, but these are not binding.[3]

To explore diversity in adolescent privacy policies and identify common approaches, we are conducting a qualitative study with key informants from different types of medical organizations in different regions of the country. The main objective is to identify diversity in adolescent privacy features within the patient portal. Another objective is to enumerate the factors involved in making portal access decisions. A third objective is to identify the potential need for more formalized guidance and standards on privacy features within the patient portal.

Methods

We are conducting semi-structured interviews with chief medical information officers and other key informants involved in informatics operations. Purposive and snowball sampling is being conducted to identify representatives from medical organizations across the four census regions of the country and multiple organizational types (pediatric hospital, community health center, non-pediatric academic medical center, outpatient practice, public hospital, etc.). The semi-structured interview guide was developed with reference to a 2012 policy statement from the American Academy of Pediatrics (AAP)[3] on ideal principles for the electronic health systems. The minimum sample size is 25, with representation of the four census regions of the country. However, in accordance with qualitative research best practices, we are conducting sampling and thematic analysis in tandem, and will adjust the target sample size upward if thematic saturation is not reached. This study was approved as minimal risk by the Weill Cornell IRB and determined to be exempt by the Georgia Tech IRB.

Results

To date, we have interviewed representatives from 26 medical centers, representing all four census regions of the United States. The most striking finding is the extreme variation in the policies regarding adolescent patient portal privacy. One policy type prohibits portal access completely during adolescence for both adolescents and parents. A second type of policy defaults to access for the adolescent only, with the parent losing access. In some of these, parents could be granted proxy access again, but the proxy rights ranged from complete access to highly limited access (for example, parents might be barred from viewing the record but be able to message with the clinician). Among those with adolescent access, the minimum age ranged from 10 to 14. However, many of the centers did not fit into either of these two policy types. For example, one granted default access for both the parent and the adolescent, and one gave default access for the parent of the young adolescent only until age 16, at which time there was no further access for anyone until 18.

Informants cited many different factors that went into the decision making of adolescent portal access. This study organized these decision-making factors into 8 underlying themes: (1) compliance with state and federal laws, (2) EHR capabilities, (3) accommodation of different types of patient needs, (4) prioritization and availability of resources, (5) insurance of patient safety/care quality and risk aversion, (6) balance of patient

autonomy/empowerment and family shared decision making, (7) community expectations, and (8) tension between teen privacy and parental preferences.

Our interviews helped highlight possible sources of assistance when making portal access decisions. Of those surveyed, most agreed that guidelines would be helpful. One informant felt that guidelines would be particularly helpful in complicated situations; such as patients in foster care or with limited mental capacity. However, there were differing opinions on the form of those guidelines. Multiple informants suggested that policy could be created with input from medical organizations, physicians, nurses, patient and parent representatives, informaticians, legal experts, EHR vendor representatives, and administration.

One informant felt that federal guidelines would be essential in the age of health information exchange when an adolescent's health information is transferred electronically from one state to the next. However, there was some concern that federal guidelines would force harmful changes to a current policy, which emphasized adolescent privacy over parental access. Another informant felt limited by state law and thought that federal guidelines would enable them to expand their policy to grant adolescents more control over their health information.

Our study identified other potential sources of assistance for medical centers. There is a need for more tech innovations, such as increased granular control of portal information, flexibility of control over the information in the portal, clearer identification of sensitive medical information, and a guarantee of privacy control. Another informant addressed the need for more research-based evidence to evaluate the importance of adolescent portal access. Importantly, there was also a call for more outreach and education to the general public on the importance of these issues when understanding parental and adolescent portal access.

Discussion

The increased use of the EHR has great implications for the adolescent patient[4], with opportunities for improved access to the medical provider and to the patient's own medical information, thereby encouraging patient autonomy. Multiple studies have found that privacy and confidentiality are vital to adolescent openness with their physicians as well as adherence to care.[5] There have been several policy statements regarding adolescent confidentiality and privacy in the electronic health record. The AAP released a policy statement in 2012[3] stating that current health information systems lack the capability to allow for protection of the privacy and security of health information for minors. The Society for Adolescent Health and Medicine stated in a position paper in 2014 that "Protecting adolescent confidentiality is a shared responsibility and requires ongoing vigilance."[6]

However, there are many different issues that factor into a medical center's decision on how to balance the tension between patient autonomy and family shared decision making. Determining the best way to handle adolescent patient portal access is challenging and involves the consideration of many issues. Therefore, it is not surprising that there is striking variation in the way adolescent portal access is handled across the country.

Our study identified potential sources of assistance in this process, including improved education and outreach, more evidence-based research evaluating adolescent portal access, and tech innovations providing more granular control. Clearer guidelines could be helpful, and could result in more consistent approaches to portal access. However, it is yet unclear who should determine these guidelines and how they should be implemented.

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