Confidentiality in Sexual Healthcare for Adolescents and Young Adults: Addressing Disclosure in the Explanation of Benefits

CHRISTINA T. CHU, BA; JACK C. RUSLEY, MD, MHS; JOHN WESLEY, JD; PHILIP A. CHAN, MD, MS; CALEB TROTZ, ScB'22; JOANNA D. BROWN, MD, MPH

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Introduction

Health insurance claims documents such as Explanations of Benefits (EOBs) are sent by insurers to inform policyholders of their – and their covered dependents' – medical visits and services to promote transparency and prevent healthcare fraud.[1] However, EOBs, which typically identify the individual who received care, the healthcare provider, and what type of care was received, may lead to unintended consequences by causing a breach of patient confidentiality. Patients, such as adolescents and young adults (AYA), may be unaware of the potential for such disclosures. In this commentary, we describe confidentiality concerns related to EOBs and how this may affect AYA when seeking sexual healthcare services. We conclude with potential policy solutions that can aid AYA and others in such situations.

Case study – access to PrEP for adolescents and young adults

In April 2019, the Rhode Island General Assembly held hearings in the Senate and House to review S.580/H.5556, a bill to address confidentiality breaches that occur with EOBs. One of the testimonies included a college student's experience with taking pre-exposure prophylaxis (PrEP), a medication preventing HIV transmission. Prior to starting PrEP, he was cautioned by healthcare providers that his parents, the primary insurance policyholders, would likely be notified about his medical visit. His parents supported his being on PrEP, but he was troubled by the lack of confidentiality involved in his sexual healthcare. In his role as a sexual health educator, he also heard from peers who opted against seeking sensitive services due to fear their personal health information would be disclosed to their parents via EOBs.

Adverse effects of explanation of benefit forms on the health of adolescents and young adults

While EOBs are designed to promote transparency, disclosure of health information to policyholders who are not the patient, in some situations, can do more harm than good. As clinical researchers and providers, we have repeatedly encountered situations where AYA, covered by parents' health insurance, are deterred from taking PrEP, or pursuing other important healthcare, due to confidentiality concerns related to the EOB. In addition to leading AYA to delay or forego care, inadvertent disclosure of healthcare information through EOBs may lead to negative mental and physical health outcomes. Care that may be affected by breaches in EOBs includes sexual and reproductive health services, substance use treatment, mental health diagnosis or treatment, and domestic violence-related care.

Regarding consent for sexual health services in all 50 states, minors under 18 may independently consent to testing and treatment for sexually transmitted infections (STIs), and adults may consent to any healthcare independently. In some states, there is a minimum age for such consent such as 12 or 14 years; RI does not have a minimum age.[2-3] RI law also allows minors to consent for outpatient substance abuse treatment if disclosure could harm the patient; for consent for pregnant teens of any age; and for consent for routine healthcare for adolescents age 16 and older.[4-5] Confidentiality violations with EOBs can lead to a chilling effect on AYA utilizing these rights to consent and seek healthcare.[5] Providing AYA with confidential healthcare is critical to improve their health outcomes.[6]

Sexual health issues and insurance coverage among adolescents and young adults

Twenty percent of the United States (U.S.) population are ages 10 to 24.[7] AYA have distinct healthcare needs including sexual and behavioral health.[8-10] Currently, AYA bear a disproportionate burden of new HIV and other STI infections in the U.S. In 2017, AYA ages 13 to 24 accounted for 21% of all new HIV diagnoses, most of whom were ages 20 to 24.[11] Half of the 20 million new STIs each year in the U.S. are among those ages 15 to 24 years.[12]

After the 2010 Patient Protection and Affordable Care Act (ACA) was enacted, millions of children and young adults gained health insurance, primarily through Medicaid expansion and a provision allowing young adults to remain on their parents' plans until age 26.[13-14] An estimated 2.8 million children from birth to age 18 years and 6.1 million young adults ages 19 to 25 gained coverage by 2016.[13-14] Compared to all other age groups, young adults ages 19 to 25 had the largest gains in coverage, with an 18% decrease in uninsured young adults from 2010 to 2018.[15] However, with

this expanded insurance coverage for AYA came the potential for more breaches of confidentiality related to EOBs. Of particular importance is the fact that EOBs for AYA up to age 26 can be sent to a parent or guardian, which can breach confidentiality.

Several studies indicate that AYA experience multiple barriers to confidential sexual health services.[8-10, 16] From 2013 to 2015, 13% of sexually active AYA covered by their parent's health insurance plan did not seek sexual or reproductive healthcare due to confidentiality issues.[16] This suggests that AYA on their parents' insurance are more likely to forgo care to avoid disclosures related to sensitive services.

In RI, there are limited options for AYA insured under a parent or guardian policyholder to obtain confidential services such as HIV/STI screening, prevention, or treatment. Biomedical HIV prevention tools such as PrEP are underutilized by AYA in the U.S. due to barriers including privacy concerns.[17-18] In our clinical experience, once patients up to age 26 learn that their healthcare services will be processed through their parents' health insurance and that disclosure may occur via EOBs, they often decide against seeking PrEP and/or HIV/STI testing. Patients could opt not to use insurance but then confront the problem that the total costs of PrEP are prohibitive, totaling $12,000 a year.[19] Providers may resort to redirecting AYA to alternative settings, like Planned Parenthood or community health centers with Title X funding, where insurance may not be billed, STI testing/treatment may be low cost or free, and confidentiality can be assured. PrEP costs remain an obstacle, and external referrals disrupt the continuity of care. Additionally, some providers may not be aware of the potential for EOB disclosures, and therefore may leave these young people vulnerable to adverse outcomes from disclosure such as conflict with parents or even physical violence.

Addressing confidentiality and explanations of benefits through state policy change

The Health Insurance Portability and Accountability Act (HIPAA) states that an individual can receive confidential communications "by alternative means or locations" if potential disclosure "could endanger the individual."[20] However, confidentiality practices regarding EOBs vary across states and may not adequately ensure that vulnerable patients are not endangered. Several states, though, have introduced legislation to address confidentiality breaches from EOBs. In 2015, California passed a law allowing patients to make a Confidential Communications Request (CCR) to redirect the EOB to a location of their choice (www.myhealthmyinfo.org). In 2018, Massachusetts passed the Protect Access to Confidential Health Care Information (PATCH) Act, mandating changes including A) using general terms on EOBs like "office visit" to describe sensitive services, B) allowing members to redirect EOBs to an alternate physical or electronic address, and C) allowing patients to suppress EOBs if no cost-sharing of the visit or the service occurred.[21] Other states have implemented additional policies protecting minor confidentiality and consent, including specific consent laws for minors to access PrEP.[3, 22]

In 2018, we formed the Rhode Island Health and Privacy Alliance (RIHPA) to address this issue. This coalition began by reviewing existing literature, partnering with key stakeholders, communicating with insurance companies and the state health insurance commissioner's office, and identifying prior efforts within and outside RI to address EOBs and confidentiality. RIHPA includes health professionals and medical societies, college health groups, and advocacy organizations working on domestic violence, reproductive health, and substance abuse issues. During the 2019 RI legislative session, as noted in the case study above, RIHPA supported legislation similar to the PATCH Act, with lead sponsors of Senator Gayle Goldin in the Senate and Representative Susan Donovan in the House. The bill did not pass, but a Senate resolution was passed recommending that the core tenets be implemented as regulation.[23] In 2020, a new bill focusing on preventing breaches of confidentiality with EOBs was proposed in the Senate. However, the legislative session was curtailed by the COVID-19 pandemic and this legislation has not progressed.

We heard alternative perspectives about EOBs and confidentiality during this process. Some insurers argued that mechanisms for redirecting and suppressing EOBs already existed. However, utilizing such mechanisms requires AYA to 1) understand EOBs and 2) have the ability to request changes. Even adult patients may not have such knowledge. Healthcare providers might be considered natural educators about EOBs; however, many are unaware of these issues as well. Additionally, insurers may not comply with requests in a timely manner without state-level policy change. Furthermore, some argued during hearings that parents should be aware of all of their minor children's healthcare. We agree that parents should be involved in children's care when possible; however, the standard of care is to provide confidentiality for AYA in sensitive situations.[6,22]

Conclusion

Evidence and our experiences suggest AYA and other vulnerable populations have been deterred from care based on EOB concerns, and their health has been put at risk from privacy breaches. More research is needed to determine the full scope of these breaches and adverse outcomes, given that occurrences are likely underreported.[1] In addition, more work must be done to identify and mitigate other threats to patient confidentiality, such as pharmacy refill reminders and online patient portals. Policies and protocols to prevent potential disclosure through EOBs should be integrated systematically at the insurance and provider level. Patient education about their rights to confidential healthcare, and education for healthcare providers, also are important for

implementation efforts. Rhode Island has an opportunity to implement such changes to strengthen access to confidential healthcare and improve overall health outcomes for adolescents, young adults, and others impacted.

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Authors

Christina T. Chu, BA, Department of Medicine, The Warren Alpert Medical School of Brown University, Providence, RI.

Jack C. Rusley, MD, MHS, Department of Pediatrics, Division of Adolescent Medicine, The Warren Alpert Medical School of Brown University, Providence, RI.

John Wesley, JD, Rhode Island Coalition Against Domestic Violence, Warwick, RI.

Philip A. Chan, MD, MS, Department of Medicine, The Warren Alpert Medical School of Brown University, Providence, RI.

Caleb Trotz, ScB'22, Brown University, Providence, RI.

Joanna D. Brown, MD, MPH, Department of Family Medicine, The Warren Alpert Medical School of Brown University, Providence, RI.

Correspondence

Joanna D. Brown, MD
Department of Family Medicine
Brown University
111 Brewster Street
Pawtucket, RI 02860
joanna_brown@brown.edu