Pediatricians have long been at the vanguard of innovation in care delivery, most recently leading efforts in participatory care in multiple areas, such as family-centered rounds. In participatory or collaborative care, patients and their families are properly empowered with information and invited to actively engage in their care. The American Academy of Pediatrics embraced this vision in a 2012 policy statement in which it elaborated that for effective participation by patients, parents, and providers, the sharing of complete health information is essential.1 The expansion of patient portals (electronic sources for patients to view their electronic health record data) has enabled the expedient sharing of more information than previously possible. Laboratory test results and diagnostic studies are part of this information, but clinical documentation (a synthesis of the provider’s thoughts and interpretation of all available data) is what completes the story. OpenNotes is an international movement that was founded in 2010 to realize this vision and advocate for patients and families to have easy access to provider documentation. Although many physicians who participated in OpenNotes were initially concerned about taking a longer time to write notes, they largely did not find this to be the reality after participating.2 Through accumulating research, patients report a better understanding of their care, and physicians endorse a stronger relationship with patients without a change in their practice.3 Ever since the passage of the Health Insurance Portability and Accountability Act in 1996, patients have had the legal right to their notes but have had to go through cumbersome steps to obtain them; OpenNotes is used to simplify this process.

Although a few pediatric centers have implemented OpenNotes, we have lagged behind our adult counterparts because of unique complexities, most notably challenges that involve documentation related to adolescent confidentiality.4 Notes may blend together multiple types of information, including sensitive diagnoses, laboratory test results, or medications, which may not be appropriate to be shared with a parent. These considerations have always been there, but as the medium of conversation is increasingly becoming digital at a rapid pace, they are drawn into sharper focus.5 Robust communication between frontline clinicians and information technology along with granular information control might help alleviate these challenges. With the proper measures
in place, the benefits of sharing notes in the pediatric setting outweigh the risks. The benefits span across several areas of pediatrics, including supporting multiple caregivers, coordinating care for children with special health care needs, and training adolescents in the transition of care.

OPENNOTES FOR PEDIATRICS

OpenNotes in the adult setting has largely been centered on the patient as the sole recipient of information. Pediatric care is unique because additional caregivers (ie, parents) are almost always involved and generally have legal decision-making capacity for most medical decisions that involve the patient. OpenNotes can be used to help multiple parents or caretakers directly read their provider’s thoughts, allowing for them to stay informed in their children’s health care even if they cannot be at the office visit. Beyond providing a synthesis of information, notes can be used to create a health timeline in a way that a snapshot of laboratory test results and problem lists cannot alone. For example, well-child visit notes may provide interval histories that offer important insights that are not captured elsewhere, such as a mildly suspicious physical examination finding that may require ongoing monitoring. Although providers may leverage emerging health information exchange systems to receive information from other health systems, they often also rely on the patient and caregiver to guide the conversation, fill missing information, and sift through previous records. OpenNotes helps families remember and refer to the often disparate amount of information that was discussed in a previous visit and reinforces families’ ability to recount relevant information. This ability to help maintain a longitudinal medical narrative between visits can be

an important safety measure. OpenNotes helps shift to a paradigm in which caretakers have access to the complete set of documentation, enabling them to fully participate in the care of their child.

One specific pediatric group that may use OpenNotes to improve outcomes are children with special health care needs, a group that accounts for 16% of the child population but 40% of the pediatric health care cost. Part of that cost has been attributed to challenges in care coordination where not having access to the full set of clinical documentation can lead to delays in care, duplicate testing, and unnecessary referrals. Currently, the health care system is plagued by fragmentation and missing information at the point of care. A parent may take a child to see a specialist, who may not have received the necessary documentation related to the health concern at the time of the visit. After the specialist’s evaluation, the primary care provider may not receive the consultation note in a timely fashion to effectively coordinate the patient’s care. By providing the parent and/or patient with their notes, they are able to take ownership of the documentation to help alleviate the current limitations in interoperability and prevent potential delays in care while waiting for a fax to come through. Even for those with limited English or health literacy, simply having their notes to share with others has been found to be useful. OpenNotes is more than just a synthesis of clinical thoughts but is used to help empower caretakers and patients to translate their situation into a language more easily understood and verified by providers.

As children become older, they may start to participate more in their own care, which is especially crucial for those with chronic illness. An adolescent with diabetes who is going to college needs to know how to order medical supplies and schedule doctor appointments; increasingly, these health management skills are being integrated into patient portals. Research has revealed that the patient portal increased adolescents’ confidence in managing their health. In this process of transition of care training from adolescence to young adulthood, there are many skills for them to learn, but one of the first steps is to have a grasp of their own medical history. Notes can be used to help adolescents understand the steps leading to a diagnosis, learn important family history, and read their doctor’s direct recommendations over time. Notes are arguably the most important component of information in a portal that is used to help weave together a patient’s health story. This issue also brings up one of the biggest challenges children’s hospitals have been facing, which is the balance of adolescent confidentiality in an era of increasing digital information transparency. Having this level of granularity of control regarding documentation sharing is a technical, workflow, policy, and ultimately a design challenge that is currently under exploration. If implemented thoughtfully, the patient portal with OpenNotes may be especially valuable in facilitating the transition of care from adolescence to adulthood.

CONCLUSIONS

OpenNotes’ magic lies within the simple act of empowering patients and their family members to have access to their full medical information so that they can participate in their care (Fig 1). Providing access to clinical documentation in addition to the laboratory test results and reports in a patient portal helps to synthesize information and provide context. The notes are a vital component for multiple caretakers to better keep track of their children’s health care
needs and for parents to better coordinate care for their child with medical complexity. Adolescent patients should be invited to participate by having access to their notes, with the necessary privacy controls in place, to prepare and empower them toward the goal of eventually taking full responsibility of their own health care. Pediatric and informatics leaders need to advocate for and work together with electronic health record vendors to help shape patient portals to thoughtfully support OpenNotes for the child and adolescent populations. Ultimately, moving toward a participatory pediatric health system will require more than design, technology, and policy changes; it will require a broader shift in culture.

REFERENCES


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