An Approach to Family-Centered Electronic Health Records in Pediatrics

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Abstract

Over the years, family-centered care in the field of pediatrics has become more prevalent and has improved the patient experience. Recent innovations within electronic health records (EHR), such as patient portals, have provided a more "patient-centered" approach by allowing patients to be interactive with the EHR and have greater agency of their own healthcare. There are also ample opportunities within an EHR to improve the patient experience with delivery of family-centered care. In this perspective, we discuss the design and use of a family-centered EHR for the purposes of optimizing the pediatric patient experience.

Keywords

electronic health record, pediatric, siblings, family-centered care

Family-Centered Care

Toward the second half of the 20th century, the practice of family-centered care in the field of pediatrics became more prevalent (1). Family-centered care is rooted in collaboration among patients, families, and healthcare providers with the following foundational principles (1):

- Respecting each child and the family (eg, honoring culture, ethnic, and socioeconomic differences and experiences)
- Tailoring care and practice to the values of each patient and family
- Sharing unbiased and complete information with patients and their families
- Empowering families to be advocates and participants in their own healthcare decisions

A classic example of family-centered care is "family-centered rounds," in which inpatient interdisciplinary work rounds occur at the bedside with families participating in the discussion and management plan. Family-centered rounds are linked to reductions in family stress and anxiety, improved staff-family communication, and enhanced family confidence (2,3).

As pediatricians, understanding how the family impacts the child's health is crucial, as a family or household can be a child's primary source of strength and support. Moreover, clinical decision-making should not only rely on the expertise of healthcare providers but should incorporate the values and beliefs of the household, ultimately empowering patients and families to be integral members of the healthcare team. It has been shown through various studies that family-centered approaches lead to increased patient/family satisfaction, decrease health care costs and more effective use of resources, and even increased provider and staff satisfaction (1). Not only does family-centered care promote a stronger alliance with providers and family but it also creates an enhanced learning environment for pediatricians to become better advocates for their patients.

Patient Experience Within the Electronic Health Records (EHR)

In contrast to experiences of care such as inpatient rounds or ambulatory visits, families do not typically interact with the

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EHR directly, although this trend is rapidly evolving with the rise of patient portals. Recent innovations such as OpenNotes, which provide patient access to ambulatory notes over secure portals, have aimed to provide "patient-centered" care and have shown benefits such as increased medication adherence and an improved sense of shared decision making (4). Other examples of a "patient-centered" EHR include "Age-Friendly Health Systems" and the Veterans Health Administration's "Whole Health Program," both of which incorporate patient goals in the development of care plans (5,6).

The term "family-centered care" is often used in conjunction or interchangeably with "patient-centered care," as in "patient- and family-centered care" (7,8). However, there are some subtle differences between the 2 concepts. Patient-centered care focuses on achieving holistic understanding by incorporating individual patient preferences and values, building relational connections and trust, and supporting patient self-management towards achieving health goals (7,8). Family-centered care extends this focus outward to include those individuals who provide support to the patient and with whom the patient has a significant familial relationship (1). A family-centered approach to the EHR has ample opportunities, such as linking medical records between siblings or members of the household (9). Each opportunity carries along with their own implications. We explore the opportunities, implications, and challenges of a "family-centered her," specifically in relation to the field of Pediatrics within the United States.

A Family-Centered Electronic Health Record

To envision a "family-centered EHR" (FC-EHR) would perhaps require some re-framing of family-centeredness as well as structural EHR functionality. Rather than being mainly "family-facing" as in the case of family-centered rounds, an FC-EHR would be primarily "team-facing," given it is the care team (eg, clinicians, nurses, social workers, medical assistants, and administrative staff) who primarily interface with the EHR. For example, a front-desk staff working to schedule a patient for an annual physical examination might, through FC-EHR functionality, be alerted to a sibling or spouse also needing annual care and could schedule multiple visits simultaneously. Similar use-cases could include immunizations and other forms of preventive care, as well as family-level medical concerns such as household exposures to COVID-19. Such applications are aligned with the American Academy of Pediatrics' idea of family-centered care coordination (10). A FC-EHR may act more "behind the scenes" and therefore improve the patient experience via more seamless healthcare delivery.

Design

The design of an FC-EHR requires input from both patients and providers and would require iterative improvement during the initial phases. Considerations need to be both patient and provider facing as well. One straightforward approach to FC-EHR design could involve linking medical records of family members, specifically siblings. Current functionality in Epic (© 2022 Epic Systems Corporation) allows search by patient phone number to identify household members (eg, siblings) sharing the same number. Sibling linkages in an FC-EHR could have wide-ranging use-case applications, including screening and referral for household-level health-related social needs (eg, housing instability and food insecurity), behavioral health interventions (eg, family therapy). It can also improve the patient experience by allowing providers to discuss the care of siblings more naturally with parents during visits with simultaneous access to healthcare information for each sibling.

Measuring Family Experience

Most importantly, an FC-EHR must be beneficial from the patient and family perspective. To date, there are no surveys or qualitative studies that explore this. Prior to the implementation of such a system, it is crucial that families are surveyed in order to build the most family-centered system. One can derive measures from experience with tools that have focused on quantifying patient satisfaction on family-centered care, such as the EMPATHIC questionnaire, used in the intensive care setting to measure family-centered practices (11). Through iterative improvements, the success of an FC-EHR should be measured as a degree of subjective satisfaction via feedback from families about their experience of care after implementation.

Challenges

Numerous questions and potential challenges arise when considering family-centeredness in EHR systems. In terms of linked charts, such as sibling linkages with an EHR, privacy, and confidentiality concerns are at the forefront. As mentioned earlier, although the advent of OpenNotes has enabled pediatric and adolescent patients to access their records, leading to better informed care, this has also led to concerns about privacy violations (12). Adolescent confidentiality, domestic violence, decision-making limitations such as cognitive impairment, and custodial transitions (or differential guardianship) all present barriers to such a design. Sibling age may be an important related consideration and sibling-linked records could work well for siblings closer in age. However, there may be legal or ethical concerns over accessing siblings' EHR data past a certain age. A possible solution would be to create linked charts that are opt-in or opt-out and have the capabilities of decoupling under certain circumstances.

On a broader system level, issues of cost, value, and impact on outcomes for an FC-EHR would require careful study and consideration of baseline EHR infrastructure. The design, deployment, and maintenance costs could be substantial and there may be challenges with quantifying

return on investment, at least in the short term. Although such a system would but most useful in the primary care setting, the evolution of such a family-centered EHR would require some degree of cross-compatibility among clinical domains, such as specialties, emergency department visits, and inpatient care. Moreover, regional and local factors also merit consideration as care-delivery systems may differ across different countries and subspecialties. Integration of an FC-EHR will need to be specifically to tailored to the hospital system in which it operates.

Furthermore, an FC-EHR dependent upon EHR linkages could alter the flow and quantity of incoming information to medical providers. Information overload could have unintended consequences for medical error rates, particularly if siblings are under the care of different pediatric providers. Measuring error rates with a sibling-linked EHR system would be of crucial importance. Decision support tools and machine learning alerts could be helpful in alerting providers to various family-level risk factors (eg, lead poisoning). Clinicians and medical staff working at the point of care should be consulted to determine optimal fit with current workflows.

Conclusions

The ideas presented here are simply intended to provide a rough sketch of what family-centeredness in the EHR might bring to the patient experience of care. A family-centered EHR can allow for improved care coordination among providers that care for multiple members of a household. The incorporation of more family-centered features within the EHR provides an opportunity for creating a health system that empowers our patients and their families, leading to improved outcomes and safer, higher-quality health care experiences.

Authors' Note

Dr. Gabbay conceptualized the project, drafted the initial manuscript, and reviewed and revised the manuscript. Mr. Hatzimemos drafted the initial manuscript, and reviewed and revised the manuscript. Dr. Bottino conceptualized the project, and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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References

1. Committee on Hospital Care and Institute for Patient- and Family-centered Care. Patient- and family-centered care and the pediatrician's role. Pediatrics. 2012;129:394–404.22291118
2. Davidson JE. Family presence on rounds in neonatal, pediatric, and adult intensive care units. Ann Am Thorac Soc. 2013;10: 152–6.23607848
3. Rappaport DI, Ketterer TA, Nilforoshan V, Sharif I. Family-centered rounds: views of families, nurses, trainees, and attending physicians. Clin Pediatr (Phila). 2012;51:260–6.21954304
4. Fossa AJ, Bell SK, DesRoches C. Opennotes and shared decision making: a growing practice in clinical transparency and how it can support patient-centered care. J Am Med Inform Assoc. 2018;25:1153–9.29982659
5. Institute for Healthcare Improvement. What Is an Age-Friendly Health System? www.ihi.org:80/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/default.aspx (2022, accessed February 2, 2022)
6. Woods SS, Evans NC, Frisbee KL. Integrating patient voices into health information for self-care and patient-clinician partnerships: veterans affairs design recommendations for patient-generated data applications. J Am Med Inform Assoc. 2016;23:491–5.26911810
7. Institute for Patient- and Family-Centered Care. Patient- and Family- Centered Care Defined. https://www.ipfcc.org/bestpractices/sustainable-partnerships/background/pfcc-defined.html (2019, accessed February 2, 2022)
8. Epstein RM, Street RL. The values and value of patient-centered care. Ann Fam Med. 2011;9:100–3.21403134
9. Wager DW. Relating multiple electronic health records. Published online 2010.
10. Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, Turchi RM, Antonelli RC, Norwood Jr KW, Adams RC, Brei TJ, et al. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. Pediatrics. 2014; 133: e1451–60.24777209
11. Rodríguez-Ruiz E, Campelo-Izquierdo M, Rodríguez MM, Estany-Gestal A, Blanco Hortas A, Rodríguez-Calvo MS, et al. Measuring family-centred care practices in adult intensive care units: the EMPATHIC-F questionnaire. Nurs Crit Care. 2021. Epub ahead of print, online June 19, 2021; 1-9. doi:10.1111/nicc.12670
12. Bourgeois FC, DesRoches CM, Bell SK. Ethical challenges raised by OpenNotes for pediatric and adolescent patients. Pediatrics. 2018;141:e20172745.29776979