Personal Health Information is Saving Grace

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As a health informatics and information management (HIIM) professional and a parent of two adopted children, my desire for complete and accurate medical information rests at the top of my "Mom to-do list." My children, Zach and Grace, are siblings, adopted at the ages of two and four from the State of Louisiana Office of Family and Child Services.

State laws vary on the provision of medical information and the provision of family medical history to parents of adopted children. We acquired a limited medical history for each child and almost no family medical history. Through diligent searching, I have been able to access additional information and recreate missing medical information through claims data and limited hospital medical records. Many of the medical records for my children have been destroyed by both hospitals and clinics.

My children have been treated for asthma and allergies most of their lives. With each visit I'm quick to tell every physician and medical professional that we encounter that my children are adopted and I don't have a family medical history for them. This is a statement that I have always believed to be valuable to the care and treatment of my children, but recently the impact of that statement and the importance of carefully maintaining their personal health information has become paramount.

In January 2014, at the request of my physician, we changed asthma and allergy specialists. After a review of Zach and Grace's past medical history, the physician requested a follow up appointment for additional allergy testing. The second visit changed our world forever. With no known family history of autoimmune disease, Grace was sent for a sweat test as a precaution when she failed to respond to the allergy testing.

Grace was diagnosed with cystic fibrosis at the age of 11. Cystic fibrosis is usually diagnosed shortly after birth. Grace was immediately seen by a pulmonary pediatric research specialist at Texas Children's Hospital. Armed with a thumb drive and a five-inch binder of medical information—which included copies of every pulmonary function test and every doctor's visit since she was two—we presented for our first visit.

When we returned for the second visit, our physician had analyzed the data and concluded that Grace never had asthma or allergies and removed her from those medications. Her analysis of the data also helped her determine a correlation between seasons and when Grace's pulmonary functions declined, finding that past episodes that were labeled "upper respiratory infection" were due to her lungs not clearing properly during periods of lower activity. Genetic testing revealed that she has a rare form of cystic fibrosis.

Her plan of treatment focuses on wellness. Grace wears a Nike FuelBand to track her levels of activity. The data collected helps to keep Grace well.   Grace journals and keeps records on her activity, diet, and how she's feeling. All of the data that she collects is shared with her care team and becomes a part of the medical record. Grace reviews her electronic medical record and is aware when additions are made to the documentation.   Records that are not available electronically are collected and added to the personal health record we keep at home. Copies are those records are shared with her specialist on each visit.

Grace communicates with her care team and is actively involved in making decisions about her care. Personal health information is saving Grace. When you meet my daughter, she appears to be the picture of wellness. That's a picture that we want to see every day, a picture that tracking data helps us to keep.

It is important to note that a comprehensive past medical history enabled Grace's physician to quickly assess and create a plan of treatment specific to her needs. A complete medical record, cradle to current medical history, was not available electronically and was not easy to obtain. I went to every care provider that has seen my daughter since the age of two. I requested copies of complete medical records. For those medical records prior to her adoption, I went to local clinics and hospitals near the location where my children were placed in foster care for the first few years of their lives and requested any available medical or claims data. Most early medical records had been destroyed but the claims data and with associated charges and ICD-9-CM diagnosis codes remained. From claims data, I was able to reveal an early history of acute and chronic respiratory illness and the treatment that was provided.

Acquiring medical data from local family physician and pediatrician was fairly easy. I requested the medical information and it was printed from the electronic record on the day of request. All x-rays were placed on a CD and the information was provided to me and sent directly to the pediatric pulmonary specialist in Texas. While the critical access hospital/clinic utilizes an electronic medical record, interoperability between the two facilities was not possible. Not all documentation was stored in the electronic record. Both a paper and an electronic record existed for my daughter. While these records were easy to obtain others were not.

The asthma and allergy clinic, where my daughter had been seen every six months since the age of two, delayed the release of her medical records. The office immediately provided me a copy of every pulmonary function test since the age of two, but refused to release physician notes. The office manager stated that the physician would need to verify the notes and then information would be sent to the specialist after review.

The office promised to fax to my husband's office and the research clinic the following day (Saturday). The records were never received and the office was closed on Saturday. On Monday, I requested the notes be faxed directly to me at the hotel where we were staying and to the research clinic. The office manager told me that the fax on Saturday had been sent but to the wrong location. The first fax that was sent to the hotel also went to the wrong location. On the third attempt the records were received. The records were never sent from the physician to the research clinic. After receiving the information I quickly began to collate and review. Upon review, I found this statement this statement in the family medical history: "the mother states that there is no family medical history of genetic disease." The statement was entered on the first visit at the clinic. It was clearly a copy paste/copy forward in the electronic record and the entry was made on every visit that followed. That one statement ruled out cystic fibrosis as a diagnosis for that care team and possibly any care team that utilized that record.

Gracie is just one example of why a commitment to the consumer must be made that we can provide health information <u>where</u> and <u>when</u> they need it. We need a guarantee that information will be available, accessible, accurate, and complete. Copy paste and copy forward pose risks to patient care. In my daughter's case, perhaps if the information had been reviewed or audited for accuracy, she would have received an earlier diagnosis.

This audit is not just the responsibility of the care giver but also the responsibility of the patient. Patients should routinely access and review records for accuracy. Since 2003, the federal HIPAA privacy rule has given individuals the right to examine and obtain copies of their health records, yet there is still widespread misunderstanding about these rights in the healthcare community, and barriers still exist for patients and families seeking full access to health records and information.

For example (and anecdotally), the "HIPAA law" is still given as the reason a patient or another provider cannot be provided with copies of or access to health records or information--although this could not be further from the truth.

Without full access to their health information, patients and consumers are unable to make informed care decisions and the status quo--care that is not patient-centric-- continues. There is a need to ensure that barriers to accessing health information are removed--both through education of providers about patient rights and how to administer HIPAA, and through increased implementation and effective leveraging of health information technology to make information more accessible to patients, consumers, and all providers caring for the patient.

If information governance practices would have been in place, things could have been different. Information governance is not a program just for hospitals. Information governance should be thought of as the gold standard for health information and documentation practice across the healthcare ecosystem. From creation to deletion, information governance policies can support a data and information infrastructure that is as critical to the patient as the care that is provided. Governance policies must clearly define the legal health record and address retention standards. Consumers shouldn't have to recreate care from claims data or worry about their data being stolen.

Effective implementation of regulations and laws and leveraging of health information technology for sharing of health information with both consumers and other providers highlights the need for "rules of the road" or information governance. Without governance mechanisms that are agreed upon across the larger healthcare ecosystem, the US will not be able to receive full benefit from its multi-billion dollar investment in health IT, let alone advance patient-centric care. Governance is needed to have high-integrity, reliable health information that can be trusted for healthcare decision making.

The American Health Information Management Association (AHIMA) defines information governance as

a framework for managing health information throughout its lifecycle and which supports strategy,

operations, regulatory, legal, risk, and environmental requirements. It includes the processes, standards,

and tools necessary for establishing decision rights, valuation of information, and improvement of data

quality and integrity. Most importantly, information governance is based on principles. AHIMA has

identified the set of Information Governance Principles for Health Care as:

- Accountability: Senior leadership oversight and responsibility for information management
- Transparency: Information management practices and processes that are open and verifiable
- Integrity: Reasonable and suitable guarantee of the authenticity and reliability of information
- Protection: Appropriate levels of protection against breach, loss, or corruption of information
- Compliance: Information complies with applicable laws, regulations, standards and organizational policies
- Availability: Maintenance of information in a manner that ensures timely, efficient, accurate retrieval
- Retention: Maintenance of information for the period of time that takes into account its legal, regulatory, fiscal, operational, risk and historical requirements
- Disposition: Secure and appropriate disposal of information no longer required to be retained by law or organizational policies

Many of the current challenges in the healthcare industry associated with health IT have been the result

of inattention to these principles at higher levels of the healthcare ecosystem—not just at the level of

the individual healthcare entity or organization.

In addition to principles, the adoption and use of functional, semantic, and technical standards to

support the interoperability necessary for stakeholders to share information is a critical information

governance issue. This includes the ability to properly identify patients as well as locate information

about them. It also includes ensuring the proper incentives are in place to encourage their adoption,

implementation and use.

If we continue with a narrow focus on technology and without a focus on information governance processes and principles, the US will continue to experience daunting challenges related to health information exchange and sharing, patient identification, and privacy/security. Patients will continue to be at a disadvantage in trying to manage their health without appropriate, trusted information. Information governance is the new imperative for advancing the use of health IT and health information to support patient-centric care. And what about claims data? It was critical to providing a complete medical history for my daughter and the codes that remained and the charges associated with her visits helped to recreate the encounter.

Addressing the current classification system is important, too. We should have been talking about the value of patient information and the classification of disease for population health long before now. The ICD-10 implementation delay presents implications for providers, health plans, and state and federal agencies, but we must continue to advocate for ICD-10 implementation. ICD-10 will have tremendous value and impact on population health data and the consumer. It is imperative we clearly articulate to the consumer the value of accurately coded data.

Things are rapidly changing, but we must navigate that change in ways that drive better decision making for patients and the providers who treat them. As healthcare professionals, we have been applying data analytics and informatics techniques for many years. The difference now is that the data is electronic, with multiple users at multiple settings, applying multiple guidelines for collection, creation, storage, use, and deletion. Data are being generated by mobile health and personal health devices. We have to make certain that we are using clean data to create health intelligence. Care is important but the information generated is what remains when the care is complete, and we can't neglect the consumer's legacy that is left for us to preserve and protect.

Healthcare professionals encounter healthcare consumers daily. We know the benefits that access and use of personal health information can bring to the consumer and their families. But consider this: over the past year, I have written numerous appeals to our insurance company to pay for an $18,000 vest for my daughter, and I have lobbied for prescription coverage for a $1500 monthly prescription and supplement coverage for my daughter, all of which are vital to her care. I am a healthcare professional; I know how to get these things accomplished. What about the average consumer who is overwhelmed by a diagnosis and just trying to make it to the next day?

As we address these barriers, we must also keep in mind the health literacy levels of healthcare consumers. Health literacy can be defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate decisions.[1] Only 12 percent of adults have proficient health literacy according to the National Assessment of Adult Literacy. Fourteen percent of adults (30 million) have below basic health literacy. These people were more likely to report their health as poor when compare with those with proficient health literacy.[2] In our journey to remove barriers to accessible health information, we must ensure that it is understandable and actionable by consumers.

Today's models of healthcare demand a commitment to wellness. It is our challenge to educate consumers and local communities on the importance and value of personal health information. There is so much each and every one of us can do to make an incredible difference.

Notes

1. U.S. Department of Health and Human Services. 2000. *Healthy People 2010*. Washington, DC: U.S. Government Printing Office. Originally developed for Ratzan SC, Parker RM. 2000. Introduction. In *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. Selden CR, Zorn M, Ratzan SC, Parker RM, Editors. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services.

2. Kirsch IS, Jungeblut A, Jenkins L, Kolstad A. 1993. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey (NALS)*. Washington, DC: National Center for Education Statistics, U.S. Department of Education.