

Healthcare Disparities and the Role of Personal Health Records

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The Institute of Medicine defines disparities in healthcare as racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs preferences, and appropriateness of intervention.¹ Geographic isolation, poverty, lack of trained healthcare providers, and lack of consumer involvement are important factors that have contributed to disparities in the availability of quality care. In response to this disparity it has been suggested that health IT may offer solutions for both the providers and consumers of care.

For the provider, emerging telehealth and telemedicine networks provide educational offerings as well as medical consultations. For the consumer, providers, advocates, payers, and the federal government are emphasizing personal health records (PHRs) as a means of educating consumers and increasing their involvement in their healthcare. In addition to direct care measures, efforts are under way to develop medical homes linking providers and consumers at local, state, and national levels.

Health information management (HIM) professionals are strategically positioned and prepared to assist in the development and integration of personal health records and provider health IT to help reduce health disparities. This article discusses how PHRs and related technologies may be used at both the provider and consumer level to assist efforts in helping to reduce health disparities, specifically national efforts.

A Snapshot of Existing Information on Disparities

Institute of Medicine research has documented that race and ethnicity are significant predictors of the quality of care.² Several studies have documented a relationship between health care disparities and the access to quality health care. The study reports that minorities who have the same insurance, status, and income as nonminorities receive a lower quality of care.

Better understanding these problems and offering plausible solutions requires accurate and complete data describing racial, ethnic, language, cultural, and socio-economic characteristics in the healthcare setting. However, these data are often inaccurate, incomplete, and lacking in detail, or not collected at all.

Overview of the PHR

The World Health Organization (WHO) defines health as the state of complete, physical, mental, and social well-being.³ This definition requires that healthcare documentation include clinical information, information on prevention of disease, and information on maintenance of wellness.

The medical record has evolved to include a longitudinal chronicle that spans from birth to death. However, individual healthcare providers maintain only the portion of the episode of illness which they treated. This has resulted in a fragmentation of a person's health story across multiple providers. Therefore, if a comprehensive, longitudinal chronology is to be achieved, the individual patient must provide the link between providers and episodes of care. The patient must also supply information about nonprovider-directed care.

In order for patients to fulfill this role, they require tools and resources for documenting and maintaining healthcare records. The integration of the PHR as part of a comprehensive record within an interoperable provider network can empower the individual consumer and allow providers to become more involved healthcare documentation and education.

The PHR may be an important tool for collecting, tracking, and sharing up-to-date clinical information about an individual's health or the health of someone in their care.⁴ PHRs can be used to help inform provider decisions. AHIMA defines a PHR as a universally available, lifelong resource kept in a secure and private environment, whose access is determined by the owner and kept separate from the provider's legal medical record.⁵ PHRs are beginning to gain acceptance as an important part of a patient's total health care record. Individuals typically compile and maintain a PHR, however emerging trends show that PHR's may also be initiated and supported by employers, insurance companies and providers as part of the medical home movement

The content of a PHR generally include medical reports with additional information provided by the patient. A typical PHR document may include the following:

- Personal identification; emergency contacts
- Contacts for physicians, dentists, and specialists
- Health insurance information
- Advanced directives; organ donation information
- Significant illnesses and surgeries; allergies
- Medications and dosages; immunizations
- Eye and dental records
- Family history⁶

PHR Impact on Disparities

The use of PHRs can reduce disparities in the level of, or access to, treatment. This in turn may have an important impact on helping reduce health disparities. PHRs help augment patient-provider communications and improve the quality of care. PHRs may also help to increase consumer awareness, involvement, safety and self-efficacy.⁷

Hurricanes Katrina and Rita brought to national attention the benefits of using electronic, portable PHRs. As the hurricanes destroyed paper records and forced evacuees to seek care away from home, many individuals faced a medical critical disruption in their treatment for chronic conditions. A large percentage of those affected were elderly people from low-income racial and ethnic minority groups.⁸ In such situations, a PHR can help patients ensure continuity of care in situations. Even in nonemergency situations PHRs facilitate management of chronic conditions by tracking use of treatments, medications, and lab values.

PHRs hold potential for reducing health disparities through an educated consumer empowerment. By facilitating timely access to pertinent health data, PHRs allow patients to take a more active role in their healthcare, even in cases of disaster.

PHR Use in Bridging Geographic Isolation

To address healthcare disparities that results from geographic isolation, Mississippi is creating an integrated and interoperable health IT infrastructure to support telemedicine, telehealth, and patient education initiatives. The project includes both provider and consumer focuses.

An integral part of the initiative is use of PHRs tied to a central data repository. The aim is to overcome structural barriers to quality care so that integrated electronic health record systems will be connected (both clinical and financial data bases) at the point of patient care.⁹ Administrative, clinical, care management, financial, and information systems must be integrated with patient information in order to:

- Support patient self-management
- Provide evidenced-based clinical decision making in underserved areas
- Improve the health status of underserved communities and populations
- Enhance safe, efficient, effective, and timely of care for all Americans
- Provide patient access to health information
- Support rapid response to emergency situations

Although technology will not be a cure-all for the nation's healthcare problems, it can serve as a conduit to improved care and reduced disparity in the access to quality care.

PHR Use in Family History Projects

Having direct access to family health history helps individuals and providers identify potential health risk and act to to reduce them. Diseases that run in families are often genetic. Many genetic mutations occur more frequently in specific ethnic groups than in the general population. Learning about family history such as ancestor's countries of origin can help determine risk for certain diseases.

To help meet this need, the Surgeon General promotes Thanksgiving as National Family History Day. Individuals are encouraged to talk to family members, especially elders, about their health conditions and the effect of these conditions on the family tree. The Chicago Center for Jewish Genetic Disorders promotes a similar initiative during the Passover holiday.

The US Surgeon General's Internet-based family health history tool, My Family Health Portrait, helps consumers assemble and share family health history information. It can help practitioners make better use of family health history information in order to provide more informed and personalized care for their patients.¹⁰

Key features of My Family Health Portrait include:

- Personalization of care
- Convenience of use
- Consumer control and privacy
- Ability to share
- EHR-ready, decision support-ready –
- Downloadable, customizable

Barriers to PHR Use

Despite the positive potential of PHRs, important barriers exist. A report from Mathematica Policy Research described the digital divide as the greatest problem associated with PHR use. Nine of 16 respondents in focus group discussions either lacked computer access or were unfamiliar with the technology.¹¹ In addition, the report noted PHR use is negatively correlated with low health literacy and cultural differences. Focus group participants who were Spanish-speaking Latinos felt that doctors avoid the use of interpreters due to time and cost issues.

Finally, there is a lack of trust with the use of computer technology for personal health data. These barriers will need to be addressed in order to facilitate effective use of PHRs in mitigating healthcare disparities.

Role of HIM Professionals

HIM professionals are well-positioned to educate consumers on the value and benefits of PHRs. The American Health Information Management Association (AHIMA) Web site myPHR provides information for the public on creating and maintaining a PHR as well as education on the related privacy issues. The site includes a free paper PHR form in both English and Spanish, as well as links to electronic PHR products, both free and paid.

An AHIMA consumer education campaign encourages HIM professionals to get involved involved with PHRs by working directly with consumers. The campaign encourages consumers-especially caregivers, maturing adults, parents raising children, and individuals managing chronic conditions-to create and maintain comprehensive PHRs that contain the information needed to make important medical decisions.

HIM professionals can serve as the bridge linking healthcare providers with consumers in the following areas:

Design and testing of PHRs. HIM professionals can be active advocates in designing PHR tools that are sensitive to underserved populations. Well-designed forms can overcome health literacy deficits. They should be designed to capture

accurate information and be understandable to both the patients and providers. Testing of resources in development should include minority populations so their concerns are identified.

Distribution of PHRs to consumers. Cultural differences can be a barrier to PHR adoption. HIM professionals can address various groups using lay terminology to tout the benefits of PHRs and train consumers to become effective users.

Training providers and consumers. Having active, informed patients is often a paradigm shift for both providers and consumers. HIM professionals can facilitate information exchange between providers and patients, who often use differing language to describe medical conditions. They can also assist consumers, especially the elderly, in overcoming the digital divide.

Protecting confidentiality. HIM professionals can communicate safeguards to protect privacy for various PHR formats. Many consumers do not trust electronic systems to protect their privacy. HIM professionals are experts on privacy regulations and procedures for both the paper and the electronic world.

Consumer Acceptance

Many people are not waiting for the federal government's proposed system of interconnected provider electronic medical records and are taking matters into their own hands, according to a report from market research and consulting firm Morpace. Twenty-seven percent of adults in a Morpace survey released in December 2008 said they are extremely likely or somewhat likely to create an online personal health record to help track their medical history and medications.¹²

This movement is being driven by the availability of new technology as well as by people's desire to take control of their own healthcare and have manageable access to their medical information, according to Morpace. Internet giants Google and Microsoft, along with traditional online health service companies such as WebMD and Revolution Health, now offer online personal health record services at no charge. As awareness of these kinds of services builds, many people will be open to using them.

As domain experts in the use of technology in healthcare, HIM professionals have an integral role in developing, promoting, and researching the use of PHRs. The HIM profession must serve as the liaison between healthcare providers and the public in creating transparency and trust within the healthcare network. This work can be directed toward the betterment of health in the general population and the reduction of healthcare disparities.

Notes

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