

PERSPECTIVE

Family Caregivers and Consumer Health Information Technology

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Health information technology has been embraced as a strategy to facilitate patients' access to their health information and engagement in care. However, not all patients are able to access, or are capable of using, a computer or mobile device. Although family caregivers assist individuals with some of the most challenging and costly health needs, their role in health information technology is largely undefined and poorly understood. This perspective discusses challenges and opportunities of engaging family caregivers through the use of consumer-oriented health information technology. We compile existing evidence to make the case that involving family caregivers in health information technology as desired by patients is technically feasible and consistent with the principles of patient-centered and family-centered care. We discuss how more explicit and purposeful engagement of family caregivers in health information technology could advance clinical quality and patient safety by increasing the transparency, accuracy, and comprehensiveness of patient health information across settings of care. Finally, we describe how clarifying and executing patients' desires to involve family members or friends through health information technology would provide family caregivers greater legitimacy, convenience, and timeliness in health system interactions, and facilitate stronger partnerships between patients, family caregivers, and health care professionals.

KEY WORDS: health information technology; electronic health records; family caregivers.

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BACKGROUND

Health information technology has been widely embraced as a strategy to facilitate patients' access to their health information and participation in care.^{1,2} Defined as technologies that are "primarily consumer-oriented but that intersect with health information technology that is more conventionally used within the context of health

care delivery,"¹ consumer health information technologies include secure internet portals that enable access to health information in an electronic medical record, personal monitoring devices, secure e-mail messaging between patients and health care providers, and Internet-based resources for health education, information and advice.

Although consumer health information technology encompasses patients, families, and caregivers,¹ the predominant focus to date has been directed at expanding access and use by patients. An important challenge of efforts to empower patients through the use of health information technology is that not all patients have access, or are capable of using, a computer or mobile device to manage their health.^{3,4} Individuals who are older and with less education, worse cognitive function, and more limited technology experience are less likely to use a patient portal,^{5,6} and they are less able to perform health management tasks electronically.^{7,8}

People with some of the most complex and costly health needs navigate the fragmented health care and social services delivery environments alongside family members and close friends. These "family caregivers" (broadly defined as family members or friends who lie outside the formal health care system) schedule and attend medical appointments, coordinate care, manage medications, assist with self-care tasks, and facilitate transitions across settings of care, among other activities. The presence and preparedness of family caregivers to undertake health management tasks affects a range of health and health services outcomes,⁹ but their role in health information technology is largely undefined and poorly understood.¹⁰ In the recent report "Family Caregivers are Wired for Health," most family caregivers reported that they are equipped with internet access and search for health information online. Nearly eight in ten family caregivers stated that they communicate with health professionals, but they overwhelmingly reported these interactions to occur offline.¹¹

In light of high visibility security breaches, ensuring the privacy and security of electronic health information is understandably of great concern for health systems, providers, and patients. The Health Insurance Portability and Accountability Act and its Privacy and Security

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Rules strive to balance the protection of individually identifiable health information with appropriate use in delivery of care. The Rules provide patients and their personal representatives' right of access to health information, and permit sharing identifiable health information relevant to a patient's care with involved family members or friends.¹² However, confusion regarding interpretation of these Rules,¹³ complexity in the application of these Rules for specific sub-populations such as adolescents and persons with questionable capacity,^{14,15} and provider prioritization of safeguarding electronic health information over its disclosure,¹⁶ have collectively resulted in practices that inhibit family caregivers' access to health information as desired by patients.¹⁷ Health system privacy rules were cited in one study as impeding health information access by nearly half (48.6 %) of family caregivers with technology experience.¹⁸

Many electronic health record vendors support functionality that allows patients to share access to their patient portal account with family caregivers through a consumer-facing "proxy" portal. National information regarding the use of shared access does not exist, but emerging evidence suggests that implementation of this functionality by providers has been variable,¹⁹ and that uptake by patients and families is limited.¹⁰ In the absence of simple and transparent processes to access patient health information with their own credentials, some family caregivers may instead interact with the health system under the guise of being the patient, using patients' credentials (see Box 1).²⁰ As consumer health information technology becomes more mainstream, the ability of providers to differentiate the identity of *who*—the patient or an involved family member or friend—is exchanging secure email messages, refilling medications, and viewing patient health information will become increasingly important in the delivery of safe and clinically appropriate care.

Mary is a high school teacher with 3 teen-age children. Mary's mother, Jane, is 75 years old, has diabetes, hypertension, early stage memory loss, and is recently widowed. Mary has gradually taken a more active role in her mother's care. Jane's primary care doctor uses an electronic health record with a patient portal. Jane's mail order pharmacy has a web application for managing medications. With Jane's permission, Mary has taken to using these tools, but has found that she must pretend to be her mother. This makes Mary uncomfortable, as she has been teaching her students and her children the importance of Internet security.

OPPORTUNITIES FOR PURPOSEFUL INVOLVEMENT OF FAMILY CAREGIVERS

Strategies that clarify and execute patient desires to involve family caregivers in the use of consumer health information technology could help bridge the digital divide for vulnerable, costly, and clinically important sub-groups of patients. Respecting patient wishes for more explicit and purposeful involvement of family caregivers in consumer health information technology would advance clinical quality and patient safety by increasing the transparency of patient health information, and would facilitate appropriate and meaningful engagement of family caregivers in supporting patient self-management and health system interactions, as follows.

Capturing and Executing Patient Preferences for Family Involvement. Although patients overwhelmingly desire

control over their electronic health information, preferences for sharing personal information with others vary widely.^{17,21,22} Affording patients the ability to specify preferences and consent for sharing health information through granular privacy control is now technically feasible, and is actively being studied.^{23,24} Granular role-based functionality allows patients the ability to selectively authorize which individuals may interact with the health system on their behalf, as well as what specific privileges they are granted.^{17,25} For example, a patient might choose to authorize a paid attendant to schedule appointments or refill prescribed medications, while electing to withhold privileges to view their health information. In one survey, veterans were twice as likely to endorse delegating authority to request prescription refills (87 %) than communicating with health care providers (40 %) on their behalf.¹⁷ As not all family caregivers are personal representatives with legal authority to access pa-

tients' health information, providing patients the ability to differentiate a greater range of authorized roles would facilitate

beneficial information access among family caregivers, as desired by patients (see Box 2).

Joe is the father of an adult daughter, Anne, who has Down's syndrome and lives in a group home. Anne has a number of chronic medical conditions, including diabetes, a heart murmur, and sleep apnea. Joe is deeply knowledgeable about Anne's health and makes sure that her medications are filled and that her doctor's appointments are scheduled. Recently Anne's primary care doctor offered Joe and Anne access to Anne's medical information through a patient portal. Anne was given her own account and with Anne's permission, Joe was granted shared access to Anne's account. Joe now schedules Anne's appointments online at a time convenient for both of them. He refills her medications, tracks Anne's diabetes labs, and views the notes from Anne's visits with her diabetes educator. Anne's doctor can receive messages from either Joe or Anne, and may easily distinguish who is asking a question and respond back to either Joe, Anne, or both.

Improved Quality Through Transparency. In the absence of widespread electronic interoperability, patients and families often are the conduit of information between providers of health care and long-term services and supports.^{26,27} Breakdowns in communication are common when patients are discharged from one setting to another, such as from the hospital to home.²⁸ Because family members and friends often bridge settings alongside patients,^{26,29} timely access to accurate information about the patient's health and discharge plan could improve transitional care³⁰ and help avert risky or redundant diagnostic procedures when a patient is incapacitated and unable to communicate.

Family Involvement in Self-Management and Medical Decision-Making. Many people with chronic and disabling conditions co-manage or delegate health management activities to others.^{31,32} However, family members and close friends are often not aware of patients' specific health issues, treatment recommendations, or care goals and consequently may not know how to best support lifestyle and medication treatment regimen adherence^{29,32,33} or decision-making preferences.^{34,35} Consumer health information technology is increasingly being used to engage patients in chronic and preventive care.¹⁶ Extending such strategies to include family members and friends could facilitate more proactive and impactful involvement of family in patient self-management efforts.^{36,37} As iterative discussions between patients and their health care providers are central to advanced care planning, health information technologies that facilitate more inclusive and transparent documentation of patient-provider

interactions could better prepare family members who are called to serve as surrogate decision-makers in critical or end-of-life care.³⁸⁻⁴⁰

Stronger Family Caregiver-Health Care Professional Partnerships. Clarifying patients' desires to involve family members or friends in their care through consumer health information technology would provide greater legitimacy, convenience, and timeliness in family caregivers' health system interactions, and facilitate stronger partnerships with health care professionals.⁴¹ Although health information technology is not a substitute for face-to-face interactions between patients and health care providers, it may nevertheless support information exchange and continuity of care.⁴² Identified advantages of asynchronous communication include convenience, efficiency, and electronic documentation of interactions.^{43,44} Greater involvement of family caregivers in secure messaging, as desired by patients, could enhance coordination of care and increase the likelihood of including the appropriate persons (including both patients as well as multiple family members) in important medical decisions. Affording family members or close friends who live at a distance and cannot be physically present at the bedside with more timely and accurate information would enable them to better understand treatment decisions and engage in family discussions about care or participate in remote family conferences. Emerging evidence suggests that telemedicine offers the potential to improve communication between health care providers and in-home family caregivers, such as in hospice care.⁴⁰

Facilitating Family Caregiver Involvement in the Learning Health System. As engaging patients and families as partners in the process of learning is a core feature of the learning health system,^{45,46} more explicit family engagement through consumer health information technology could strengthen meaningful care delivery redesign and practice improvement. For example, family caregivers could be recruited to assist in monitoring patient symptoms or events (e.g., falls), participate in quality reporting, or provide feedback regarding provider processes and workflows. As family members are among the most vigilant of health system stakeholders, affording them the ability to alert providers of inaccuracies or omissions in the patient's electronic health record could enhance patient safety. Because patients and knowledgeable informants commonly diverge in their ratings of patient health⁴⁷ and quality of care,⁴⁸ the ability to differentiate patient from family caregiver identity would allow learning health systems to meaningfully interpret patient-reported data capture when contributed by someone other than the patient.⁴⁹

FUTURE DIRECTIONS

Three issues will require careful attention if family caregivers are to be more widely and purposefully engaged in the use of consumer health information technology. First, electronic health record and personal health record vendors must better accommodate the reality that patients' information sharing preferences are nuanced and evolve over time,^{22,50} by incorporating user-centered design principles to develop shared access functionality that better reflects patient preferences.⁵¹ Second, best practice implementation strategies are needed to guide provider policies and processes for credentialing and registering family members to access patients' health information. To this end, organizational strategies that promote patient adoption and use of the provider-sponsored personal health record⁵² should be expanded to consider how to promote explicit credentialing and registration of family members and friends. The Office of the National Coordinator for Health Information Technology is well positioned to disseminate best practices through education and outreach through Regional Extension Centers, HIT.gov, and partnerships with professional societies and credentialing organizations. Third, organizations and federal and state governmental agencies tasked with monitoring the spread of consumer-facing health information technologies should provide equal weight and attention to patient and family adoption in tracking diffusion and use. Accreditation organizations such as the National Committee for Quality Assurance should incorporate proxy portal availability and rates of registration for particular patient subgroups (e.g., patients with dementia) or

programs (e.g., Patient Centered Medical Homes) to serve as quality measures that pertain to patient and family engagement.

With the convergence of population aging, rising costs, and the diffusion of health information technology, strategies to explicitly credential and purposively include family caregivers in the design and implementation of health information technologies will only grow in importance. Adoption of a secure online identity ecosystem to guarantee private credentials, now in development,⁵³ could facilitate broader electronic credentialing and registration of family caregivers. As learning health systems seek to deliver high value care, reliable electronic interactions informed by appropriate credentialing of patients and families would facilitate more appropriate and efficacious delivery of care and more impactful strategies to engage patients and families. Broader inclusion of family caregivers in the use of health information technology as desired by patients would further National Quality Strategy priorities, including ensuring that each person and family is engaged as partners in their care, promoting effective communication and coordination of care, and reducing avoidable harm.⁵⁴

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Conflict of Interest: The authors declare that they do not have a conflict of interest.

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