Care Partners and Online Patient Portals

**Each year,** more than 65 million people in the United States (29% to 39% of the population) provide care for a chronically ill, disabled, or elderly family member or friend. Such caregivers, who help with both basic life functions and managing medical care, are critical to helping people maintain their health and remain in their communities. Many chronically ill and older people also have loved ones who, distinct from caregivers, serve as “care partners.” These care partners do not provide day-to-day care or serve as surrogate decision makers but do help navigate health care—facilitating communication with physicians, discussing complex issues requiring shared decision making, and assisting with challenging self-management tasks. The care partner or partners may include a spouse, parent, friend, or relative who assists with health, perhaps across geographic distance.

Health care systems today do not optimally identify or engage these individuals and frequently even push them away by creating barriers to obtaining patient information that may help in the care of their family member, often in the name of privacy and security, sometimes invoking the Health Insurance Portability and Accountability Act (HIPAA). There is potential for improving care if care partners and families can be more effectively engaged through the electronic health record (EHR): this can be accomplished without undermining patient privacy or the security of protected health information.

The United States is rapidly adopting EHRs. According to one recent estimate, 72% of office-based physicians now use EHRs, up from 48% in 2009. These EHRs are typically linked to personal health records (often called patient portals), which can help patients manage their care online via e-mail messaging with clinicians, access to laboratory test results and medical histories, and online appointment and prescription refill functions. One report indicated that 20% of physician offices have “live” patient portals, and federal requirements to receive incentives for the meaningful use of health information technology stipulate that offices have at least 5% of patients using an Internet-based patient portal by 2014. Implementation is far from complete, but portals soon may become a standard part of care. Patient portals have the potential to deliver substantial benefits, such as improved communication between patients and clinicians, greater access to a person’s own health care information, and increased patient engagement. To realize these potential benefits, both caregivers and care partners will need to be engaged—but this is not yet happening.

Patients want their care partners to engage with health systems’ online portals. In one survey of 18 471 patients, 79% said they were interested in sharing their patient portal access with someone outside their health care team. In 47% of cases, they wanted to share with someone who did not live with them. Many but not all patients wished to share with family members. It seems logical that patients should be able to grant access to others to view and help manage their health using their health system’s online patient portal. However, patient portal access on behalf of others is not easy or even permitted in many health care systems.

Because the extent of caregiving varies for different populations, one type of patient portal access would not fit all situations. For patients who lack decision-making capacity, surrogate decision makers could be granted full access to the patient portal on their behalf. This would facilitate oversight of care and communication with the health care team for an at-risk population. Many other patients—those who depend on caregivers; those who lack the inclination or ability, because of language or literacy, to engage with technology; and children—have a care partner. If that care partner could access the portal on the patient’s behalf, problems such as distance, between-visit chronic disease self-management, and the need for asynchronous modes of communication with clinicians could be addressed.

For parents or guardians managing their children’s health, issues of security, autonomy, and privacy are not straightforward. Adolescents present a particularly challenging problem. Frequently, state laws govern the access and representation of adolescents with regard to special conditions (eg, sexually transmitted diseases, contraception). Although it may be challenging for software to reliably ascertain the application of multiple, sometimes contradictory state laws, innovative health systems such as Children’s Hospital in Boston, Massachusetts, have implemented a policy that allows for children’s portal access to transition from parent-only access to patient-only access in a tailored fashion, depending on the sensibility of the information and the patient’s age.

For patients who have decision-making capacity but regularly call on care partners for input or assistance, patient portal access could be more nuanced. Some patients may be inclined to simply share with their care partners the user identification and password to their patient portal. However, this may create confusion because electronic communications from the patient or care partners to the health care team will not be distinguishable. Using distinct credentials/authentication for care partners would allow patients to determine which types of information they would like to share. For example, details of diabetes management could be shared with family members, whereas mental health treatment could be kept private. Moreover, granting separate credentials allows for periodic reauthentication and, if needed, revocation of care partner access.
From a technical perspective, shared access to patient portals is solvable. For example, a specific permission process allows Kaiser Permanente members to grant family access to the patient portal to view information and take actions (eg, requesting refills and making appointments) but only if the family member also is a Kaiser Permanente member.

Several barriers hinder advancement in this realm. First, although the Office of the National Coordinator acknowledges the importance of caregivers and family, broadly adopted standards for caregiver access to patient portals are not available. Such standards often drive the necessary technical innovations that would make sharing portals simpler from a software design perspective. Second, strong authentication ensuring both patient permission to share access and identity confirmation of the care partner would be needed, and health systems are understandably reluctant to create potential privacy breaches. However, if a health system required in-person visits to establish patient portal access for individuals, a standardized, rigorous (but practical) authentication guideline could help allay health system concerns and individual data security concerns.

Several specific steps could advance progress in this area. Health care organizations need to begin to identify approaches to routinely identify and document caregivers and care partners in their EHRs. Furthermore, the meaningful use criteria should specifically detail the need for designated caregiver access. Federal support for developing standards in this area should be provided. Federal support for research should be made available for demonstration projects to understand how to best provide access to personal health records for patients with caregivers, children and adolescents, and adults with high or complex health needs with care partners, and to assess the benefits of doing so.

While challenges exist, doing the necessary groundwork to enable care partners—not just health care proxies—to access personal health records could represent a key catalyst in enabling care coordination and delivering on the potential of technology to enhance health care and, ultimately, improve health.

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REFERENCES