

The Great Divide: Clinician, Family Caregiver and Patient Perspectives

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The Family Caregiver Point of View

There is a new normal in the United States: 39% of adults¹ provide an estimated \$522 billion² in care to their loved ones. Imagine the economic impact on the healthcare system were it not for the dedication of family caregivers. In fact, family caregivers are the most underutilized resource in the healthcare system, even though they occupy the front lines of care delivery and care coordination. They are medical record keepers, medical decision makers, insurance navigators and medication administrators, just to name a few of the numerous roles. In general, the following problems are rampant in the healthcare system, challenging the family caregiver at every step:

- Lack of recognition of the family caregiver role and its importance.
- Absence of dialogue between providers and a family caregiver.
- Use of complex medical terminology and insurance jargon.
- Lack of training/education to familiarize a family caregiver with next steps in recovery or how to perform caregiving tasks.
- Inadequate access to their loved one's medical information.
- Misinterpretation of HIPAA that further impedes family caregivers' access to information.
- Clinical workflows/processes that don't incorporate a family caregiver.
- Absence of a care plan created in partnership with a family caregiver.
- Lack of coordination between healthcare and social services.
- Inadequate collaboration between providers.
- Poor care transitions between settings of care, especially to the home.
- Woeful lack of reimbursement to cover long-term home care needs, home modifications and sensor technology, for example, to support keeping family members in a home setting.

Clinician, Patient Points of View: Lack of Information, Communication

Doctors and other clinicians do not always have the necessary information, such as summaries from other clinics, hospitalizations and emergency room visits, to address the needs of their complex care patients. During short visits, patients often do not share important information about their health problems and may not even fully understand how some of their problems could affect their health. Without more complete information, clinicians miss important clues about their patients' abilities to manage in their current environment.

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A new kind of healthcare professional, a care coordinator or health coach, can help patients and families access the help they need and make sure information is shared among clinicians. In addition, tools are improving clinical and financial

outcomes since they were first introduced in the 1990s, and the evolution will likely continue for the next decade as patients and families better understand how to utilize them.³

Consumers regularly communicate with non-healthcare service providers so they can make more informed choices, but it has been more difficult for consumers to apply the same questions to healthcare. Right now, patients with serious health problems are not able to find the products and services they need when and where they need them. As patients and families spend more of their own money for health-related products and services, they are beginning to demand better information that helps them navigate the healthcare marketplace.

Today, patients and family members do not (and perhaps cannot) prepare for health conditions that are likely to arise. They may have little insight into their risks and little ability to predict what will happen if they choose one option over another.⁴

Information found in medical records provides little insight into patients' abilities to effectively manage their health. Lab values and images provide information about current conditions and past behaviors but are not able to predict how well they can improve or maintain a patient's health. Clinicians need information about patients' symptoms and their tolerance of certain treatments to adjust medications and recommend effective interventions, and this may require more communication than a face-to-face, patient visit four times a year.

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In addition, patients need time to think about important decisions rather than make a quick decision as part of a short consultation. More communication spread over time becomes important as care becomes more complex. And more care team members need to participate in communication to evaluate patients' conditions and abilities to improve their current health status in their environment and to develop a plan that is able to achieve desired patient goals. In addition, after a plan is formulated and patients and their families accept

and understand it, measuring results and adjusting to unforeseen circumstances will require even more communication.

There needs to be a more robust national dialogue to develop strategies for overcoming these issues. At the same time, it is important to confront the realities of technology and its potential to support family caregivers in this challenging environment.

Health Tools of the Future

It is possible to get a glimpse into the future of healthcare. Relationships will continue to be important, and with new and better tools, closer ones can be maintained. Several factors are allowing patients and families to work with clinicians to produce more options and make better decisions. They include:

1. Better information about quality and outcomes and easier access allow patients to find clinicians they desire and need to address specific conditions, such as cancer. As the population ages, cancer occurs more frequently and patients and families dealing with the condition are overwhelmed with information. Studies have shown that they are not satisfied with the amount and quality of communication about their care.⁵ Some employers and payers are encouraging patients to choose "centers of excellence" for elective surgeries and complex chronic conditions as they have found that higher quality care is less costly.⁶

2. Improved communication tools and devices are available for sharing objective and subjective information. As communication capabilities improve, clinicians are finding that timely information about understanding a care plan or response to a treatment is helpful in addressing issues requiring immediate attention, such as an emergency room or hospital admission.

Higher cost interventions can be avoided by recognizing problems earlier—utilizing data from devices, surveys and more regular messaging from additional sources. Data from devices, such as weight scales, thermometers, oximeters and step counters can help clinicians recognize patterns and adjust medications and therapies. As these tools develop, better decision support tools will evolve that facilitate decision making by guiding clinicians, patients and family members through targeted questions to arrive at the best possible decisions.

3. Better, more secure information-sharing capabilities allow care team members to communicate across organizational boundaries. In order for this level of communication and data sharing to occur, there needs to be much more health information interoperability and sharing among a wider group of organizations and individuals. New technologies support more flexible data sharing and management, and newer standards are being developed that will facilitate better data flow.

Patients (and their family caregivers) need to actively access their health information and in order to reap the greatest rewards, aggregate information from various sources to create their own longitudinal records. Just as individuals review and manage their financial data, a patient, especially one with significant health concerns, could become better informed and more likely to avoid a medical error if they reviewed and became familiar with their health and medical information.

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When it comes to engagement of family caregivers as active members of a patient care team, there are many obstacles to overcome on the way to eliminating the Great Divide. If family caregivers continue to be the backbone of the healthcare system, they need the information tools required to do the job. If clinicians are expected to make adjustments to care delivery and respond to the evolving landscape, it is necessary to re-think workflow and payment models to allow them this flexibility. And finally, it is important to accept that culture change required to do these things will at times be difficult, but well worth the investment.

¹ Fox, S, Duggan M, Purcell K. "Family Caregivers Are Wired for Health." Pew Research Center. June 20, 2013.

² Chari AV, Engberg J, Ray KN, et al. "The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey." *Health Services Research*. June 2015;;50(3):871-82.

³ Milani RV, Lavie CJ. "Healthcare 2020: Reengineering Healthcare Delivery to Combat Chronic Disease." *The American Journal of Medicine*. April 2015;128(4):337-43.

⁴ "Effective Healthcare Program: Helping You Make Better Treatment Choices." Agency for Healthcare Quality and Research.

⁵ "Core Value, Community Connections: Care Coordination in the Medical Home." Patient-Centered Primary Care Collaborative. January 2011.

⁶ "Why Is a 'Center of Excellence' Different From an Institute?" The Advisory Board Company. Sept. 14, 2011.

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