What Family Caregivers Need from Health IT and the Healthcare System to be Effective Health Managers

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About the Author

MaryAnne Sterling is the Co-founder of Connected Health Resources. She has been a caregiver for her aging parents for 18+ years. She is a renowned speaker and educator on Alzheimer’s Disease and its impact on family caregivers. Her personal story has been featured in Kiplinger, New York Times, USA Today, and the Wall Street Journal.

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Introduction

What do family caregivers need from health information technology? Until recently, this is a question that few had bothered to ask. And yet, there are 93 million¹ family caregivers today in the United States who will provide an estimated $522 billion² in care for their loved ones. Imagine the economic impact to our healthcare system were it not for the dedication of family caregivers.

I am one of them. We are the perfect audience to both use and influence the development of health information technology. But these emerging tools must support our specific information needs in order to become a permanent component of our caregiving toolbox and they must be accompanied by a collaborative healthcare ecosystem in which the family caregiver is a key member of the patient’s care team.

Background

We have a new normal in the United States: 39% of adults provide care for a loved one³. That number equates to roughly 93 million people, many of whom find themselves in the middle of the caregiving sandwich, often caring for children plus a parent or spouse with a life-threatening illness or chronic condition (or simply struggling with advanced age), not to mention balancing a career.

The Pew Research Center quantified the family caregiver demographic last year in a ground-breaking report; Family Caregivers are Wired for Health:

Who Are Caregivers?
Among all adults, the percent within each group who care for someone.

<table>
<thead>
<tr>
<th>All adults ages 18+</th>
<th>Educational Attainment</th>
<th>Household Income</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NO HIGH SCHOOL DIPLOMA</td>
<td>HIGH SCHOOL GRAD</td>
</tr>
<tr>
<td>WOMEN</td>
<td>31%</td>
<td>36%</td>
</tr>
<tr>
<td>MEN</td>
<td>40%</td>
<td>44%</td>
</tr>
<tr>
<td>39%</td>
<td></td>
<td>43%</td>
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<table>
<thead>
<tr>
<th>Household Size</th>
<th>Educational Attainment</th>
<th>Household Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 ADULT</td>
<td>40%</td>
<td>$75,000+</td>
</tr>
<tr>
<td>2 ADULTS</td>
<td>41%</td>
<td>$50,000-$74,999</td>
</tr>
<tr>
<td>3 OR MORE ADULTS</td>
<td>44%</td>
<td>$30,000-$49,999</td>
</tr>
<tr>
<td></td>
<td></td>
<td>LESS THAN $20,000/ YR</td>
</tr>
<tr>
<td>32%</td>
<td></td>
<td>36%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Parent of Minor</th>
<th>Non-Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>NON-HISPANIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHITE</td>
<td>46%</td>
<td>36%</td>
</tr>
<tr>
<td>BLACK</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>HISPANIC</td>
<td>39%</td>
<td>36%</td>
</tr>
</tbody>
</table>

Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults. See Appendix for further details.

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Although we know that family caregivers are utilizing online resources in greater numbers than non-caregivers and a sea of startups are beginning to develop caregiver-facing technology, there is a gap in understanding the real time data and information needs of caregivers. The purpose of information technology is to put the right information into the hands of the right person at the right time. Family caregivers are infrequently asked what information they need and when. **The purpose of this document is to provide an information framework for technology developers to use as guidance.**

Once family caregivers have the information they need to be effective health managers, they also need a healthcare system that is prepared for and willing to collaborate with them as they support a loved one’s treatment or recovery. Our current healthcare system falls short. **This document will also address the elements of culture change necessary to create a healthcare ecosystem that empowers family caregivers, including opportunities for providers to partner with family caregivers to enhance care.**

**Challenges Facing the Family Caregiver Today**

Every discussion about technology solutions should begin with an analysis of the problem being addressed. Let’s begin by level-setting how the family caregiver and the healthcare system interact today. This can best be illustrated by exploring the experiences of real family caregivers as a starting point, which we will do at the beginning of each section in the remainder of the document.

**Inadequate Collaboration:**

“I am not getting good medical care”! This is how a conversation began with my 84-yr-old mother, a retired nurse, two years ago. Issue #1: lack of response from both her primary care doc and cardiologist after she called them to report an allergic reaction to medication; and Issue #2: a complete breakdown in communication between primary care doc and pharmacy. The pharmacy could not refill critical medications for almost a week, including heart medication, until re-authorized by the non-responsive primary care doc. I became the middleman. The idea that mom’s primary care doc, cardiologist, and pharmacy are even close to working as a team and exchanging information to improve her healthcare is still not a reality.

**Access to Information:**

In Kathy’s case, the frustration revolved around access to data: “...I’ve struggled with the healthcare system as a family caregiver ... to get access to information I need to manage my mother’s low (blood) sodium, specifically, inability to get lab results electronically and in a timely manner... For months before my mother spent 4 days in the ICU because of low sodium, I had been trying to get mom’s lab results electronically. The geriatrician we use is part of a large group practice that has an electronic patient portal. However, unbelievably to me, the blood drawn at the residence where my parents live went to a lab that faxed the results back to the physician, where it was put in a paper record, which was then not accessible to me, clinicians in other locations, or the hospital.”
There are several forward-thinking organizations within the healthcare system working to partner with patients and their family caregivers. But we have a long way to go. In general, the following problems persist, challenging the family caregiver at every step:

- Lack of recognition of the family caregiver role and its importance
- Absence of dialogue between providers and the family caregiver
- Use of complex medical terminology and insurance jargon
- Lack of training/education to familiarize the 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 the family caregiver
- Absence of a care plan created in partnership with the 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, sensor technology, etc., to support keeping family members in the home setting

We need a more robust national dialogue to develop strategies for overcoming these issues. At the same time, we need to confront the realities of technology and its potential to support family caregivers in this challenging environment.

**The Caregiving Information Cycle**

**Information Gaps:**

My husband and I recently navigated the tricky waters of Medicaid eligibility on behalf of my mother. As part of that process, one of the Aging and Disability Resource Centers (ADRCs) in our state offered to assist us in our search for an assisted living facility with an empty bed. They emailed us a spreadsheet that contained the contact information for 314 assisted living facilities and informed us that we had to call each of them to find out if they accepted the Medicaid Auxiliary Grant (a Medicaid waiver program in Virginia) and if they had a bed available. Given the potential of technology, why is it that I can drive down the interstate and see the nearest emergency room wait-time on a billboard, but nobody has a database with the availability of a bed across my state’s assisted living facilities?
This is just one example of the many gaps across the healthcare ecosystem that information technology could fill. But before we go any further, we need to look at the information that family caregivers need in order to navigate their caregiving journey.

**Family Caregiver Information Needs**

Healthcare and social services information is the currency of the family caregiver. As it turns out, we need different information at different points in time, depending on the phase of caregiving we find ourselves in. I refer to this as the *Caregiving Information Cycle*.

![Caregiving Information Cycle diagram](image)

**Crisis**
- Accident/injury
- New Diagnosis

**Care Transition**
- New Care Setting
- New Phase of Recovery/Illness

**Maintenance**
- Chronic Condition
- Permanent Disability

Typically, a caregiver is either: dealing with a **crisis**, assisting a loved one through a **care transition**, or in **maintenance** mode – just trying to navigate day-to-day challenges.

Family caregivers may find themselves in each phase of the Caregiving Information Cycle many times over the course of their caregiving experience. Our information needs change as we move between phases, sometimes quickly and unpredictably. In addition, our information needs fall into 2 distinct categories: *gathering* information to act upon and *providing* information to others.

In the Caregiving Information Cycle, a **crisis** refers to an accident, injury, or new diagnosis. During a crisis, caregivers may need to provide information to healthcare professionals, including...
The patient’s:

- Allergies and health history
- Family health history
- Immunizations
- Test results/labs/films
- Health insurance

During a crisis, caregivers need to gather information, including...

- Diagnosis or injury details
- Disease-specific information
- Care options
- Next steps

**Care transition** refers to a new care setting or new phase of recovery/illness. During care transition, caregivers may need to gather information about...

- The patient’s care plan
- Housing/caregiving options (i.e. rehab, home health, nursing home, hospice)
- Community resources (i.e. meals on wheels, transportation)
- Instructions for performing caregiving activities
- Medical equipment

**Maintenance** refers to a chronic condition or permanent disability. During the maintenance phase, caregivers may need to gather information about ...

- Long-term care supports
- Financial options
- Assistive devices
- Medication regimens
- Respite care
- Support groups

The family caregiver often becomes an information expert, having compiled knowledge from several different areas, including the healthcare, social services, insurance, legal, and pharmaceutical domains.

**Family Caregiver Technology Needs**

Technology can be used in a variety of ways to support the information needs of family caregivers. In many caregiving situations, technology can be a lifeline to information, if it is intuitive and easy to access. The tech-savvy family caregiver generally has technology needs that fall into six categories: Access, Track, Manage, Coordinate, Connect, and Learn, described below:
<table>
<thead>
<tr>
<th>Category</th>
<th>Information Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>family health history, medical records, test results, medication lists, insurance statements/bills, legal documents such as healthcare proxy</td>
</tr>
<tr>
<td>Track</td>
<td>immunizations, vital signs, blood sugar, weight, food intake, mood, rest, patient location</td>
</tr>
<tr>
<td>Manage</td>
<td>medication administration, refills, and care plans</td>
</tr>
<tr>
<td>Coordinate</td>
<td>doctor appointments and referrals, in-home care and services, other family caregivers</td>
</tr>
<tr>
<td>Connect</td>
<td>with other caregivers, providers, family members, and friends</td>
</tr>
<tr>
<td>Learn</td>
<td>about a diagnosis, disease, treatment, or the latest research</td>
</tr>
</tbody>
</table>

When the technology needs of family caregivers are aligned with the Caregiving Information Cycle, we see the following:

During a **crisis**, family caregivers may need to **access** family health history, test results, and medication lists. They may need to **connect** with family members, and **learn** about a diagnosis or disease.

### Crisis

<table>
<thead>
<tr>
<th>Category</th>
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</thead>
<tbody>
<tr>
<td>Access</td>
<td>family health history, medical records, test results, medication lists, insurance statements/bills, legal documents such as healthcare proxy</td>
</tr>
<tr>
<td>Track</td>
<td>immunizations, vital signs, blood sugar, weight, food intake, mood, rest, patient location</td>
</tr>
<tr>
<td>Manage</td>
<td>medication administration, refills, and care plans</td>
</tr>
<tr>
<td>Coordinate</td>
<td>doctor appointments and referrals, in-home care and services, other family caregivers</td>
</tr>
<tr>
<td>Connect</td>
<td>with other caregivers, providers, family members, and friends</td>
</tr>
<tr>
<td>Learn</td>
<td>about a diagnosis, disease, treatment, or the latest research</td>
</tr>
</tbody>
</table>

During a **care transition**, family caregivers may need to **access** medical records, **manage** medication administration and care plans, **coordinate** in-home care and services, **connect** with providers, and **learn** about a particular treatment.

### Care Transition

<table>
<thead>
<tr>
<th>Category</th>
<th>Information Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>family health history, medical records, test results, medication lists, insurance statements/bills, legal documents such as healthcare proxy</td>
</tr>
<tr>
<td>Track</td>
<td>immunizations, vital signs, blood sugar, weight, food intake, mood, rest, patient location</td>
</tr>
<tr>
<td>Manage</td>
<td>medication administration, refills, and care plans</td>
</tr>
<tr>
<td>Coordinate</td>
<td>doctor appointments and referrals, in-home care and services, other family caregivers</td>
</tr>
<tr>
<td>Connect</td>
<td>with other caregivers, providers, family members, and friends</td>
</tr>
<tr>
<td>Learn</td>
<td>about a diagnosis, disease, treatment, or the latest research</td>
</tr>
</tbody>
</table>
During **maintenance**, family caregivers may need to **track** a patient’s blood sugar or weight, **manage** refills, **coordinate** doctor appointments and referrals, **connect** with other caregivers, and **learn** about the latest research on a particular course of treatment.

<table>
<thead>
<tr>
<th><strong>Category</strong></th>
<th><strong>Information Needed</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Access</strong></td>
<td>family health history, medical records, test results, medication lists, insurance statements/bills, legal documents such as healthcare proxy</td>
</tr>
<tr>
<td><strong>Track</strong></td>
<td>immunizations, vital signs, <strong>blood sugar</strong>, <strong>weight</strong>, food intake, mood, rest, patient location</td>
</tr>
<tr>
<td><strong>Manage</strong></td>
<td>medication administration, <strong>refills</strong>, and care plans</td>
</tr>
<tr>
<td><strong>Coordinate</strong></td>
<td><strong>doctor appointments and referrals</strong>, in-home care and services, other family caregivers</td>
</tr>
<tr>
<td><strong>Connect</strong></td>
<td>with other caregivers, providers, family members, and friends</td>
</tr>
<tr>
<td><strong>Learn</strong></td>
<td>about a diagnosis, disease, treatment, or the <strong>latest research</strong></td>
</tr>
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</table>

Understanding the information and technology needs of family caregivers is imperative when developing information systems and tools that address these needs.
Reality Check. We have technology. Now what??

Family caregivers are using a variety of technology, but it’s dependent on the comfort level of the user and the complexity of the problem they are trying to solve.

Examples of Current Technology Solutions:

The Nelson family relies on spreadsheets: “I use excel to create records that captured the data I needed over time, to keep up with all of Dad’s medications (ordering them, making sure the prescriptions were right and up-to-date, and keeping track of what I gave him). I even used excel to make a spreadsheet that helped me fill up the weekly dispenser in a way that was more accurate and made the task faster to do.”

For the Connors family, email plays a role: “We use email with home health care providers so mom has a steady team of companion caregivers.”

The Mazza family turned to simple technology, generally used to monitor a much younger generation: “A few years ago, we cared for my mother, who was in an apartment across the street from my music store. We couldn’t leave her alone because of Alzheimer’s, but after she went to bed I had a wireless baby monitor system that allowed me to see if she got up. I could watch from my instrument repair workbench across the street and get my work done…”

Emerging Technology:

Lynn is applying new technology in novel ways to document “a day in the life” of a family caregiver. She is using a GoPro to “capture as much as I can of our day and what we do” in order to share what they’ve learned “so others can have a better quality of life.”

Apps are beginning to appear in the daily routines of caregivers. I recently met Loretta, an Alzheimer’s caregiver, who uses three apps to help care for her mother. Each has a unique focus:

1) ideas for the caregiver on how to deal with difficult behavior
2) music to soothe sun-downing behavior (people with Alzheimer’s often get more agitated when the sun goes down)
3) reminiscing about days gone by (to engage her mom)

Technology Available Now

There is a vast array of technology that the family caregiver can turn to in support of their information needs. This ranges from patient portals to wireless sensors, to devices that determine whether or not a
patient has taken their medication, to online appointment scheduling and support communities. If we look at these tools using our technology categories, we find:

<table>
<thead>
<tr>
<th>Category</th>
<th>Information Needed</th>
<th>Types of Tools Represented</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Access</strong></td>
<td>family health history, medical records, test results, medication lists, insurance statements/bills, legal documents such as healthcare proxy</td>
<td>personal health records, patient portals, Blue Button</td>
</tr>
<tr>
<td><strong>Track</strong></td>
<td>immunizations, vital signs, blood sugar, weight, food intake, mood, rest, patient location</td>
<td>wireless sensors, i.e. mats in the bathroom and kitchen that indicate if mom has fallen; GPS safety devices, health and exercise apps</td>
</tr>
<tr>
<td><strong>Manage</strong></td>
<td>medication administration, refills, and care plans</td>
<td>medication reminders, devices that determine whether or not patient has taken their medication (and provide the correct dose), care planning tools</td>
</tr>
<tr>
<td><strong>Coordinate</strong></td>
<td>doctor appointments and referrals, in-home care and services, other family caregivers</td>
<td>online appointment scheduling, apps to help coordinate multiple family caregivers</td>
</tr>
<tr>
<td><strong>Connect</strong></td>
<td>with other caregivers, providers, family members, and friends</td>
<td>on-line support communities, secure email</td>
</tr>
<tr>
<td><strong>Learn</strong></td>
<td>about a diagnosis, disease, treatment, or the latest research</td>
<td>countless health and medical information sources, blogs</td>
</tr>
</tbody>
</table>

At first glance, it may appear that a wealth of information technology tools exist to support family caregivers. However, a deeper dive reveals a more lackluster picture. Very few tools are designed specifically for family caregivers and their information needs. Conversely, the availability of these tools does not guarantee access to information. Electronic access to personal health data is spotty. Blue Button is still in its infancy. It is difficult to obtain medical records.

From the caregiver’s perspective, finding time to incorporate new technology into daily routines is often prohibitive, along with the applicability of technology to real-life caregiving scenarios. In addition, uncoordinated technology (e.g. multiple patient portals) may simply create more silos. Trying to keep track of multiple technology tools and the data they generate could be more trouble than its worth at some point.

Not all caregiving challenges can be solved with technology. Caregiving is a complex web of tasks that turn everyday people into care coordinators, medical record keepers, medical decision makers, insurance navigators, medication administrators, and deliverers of complex medical care.

Technology can assist in making some of these tasks easier, but it’s not enough. Just navigating the healthcare system is a monumental task that would be so much easier if caregivers had access to care navigators or similar people who could assist them through the maze of services, jargon, and red tape. People who speak in the same way they do. The language of healthcare is not the language of the average American.

And there are other barriers...
Care Plan

- Widespread adoption of existing family caregiver technology is painfully slow. Getting the word out to 93 million people is challenging and, right now, not being done in a coordinated fashion. Family caregivers simply don’t know what tools are available to them.
- Information on the web is not curated and written at a high literacy level. It becomes a mine field for caregivers to find, sift through, and comprehend medical information.
- Connectivity/monitoring do not imply “action”. They must be coupled with people in the community (in addition to first responders) who can take action when red flags arise.
- Patient (and Caregiver) Generated Health Data are not widely accepted and no framework exists for receipt/review/response. Last year, the Patient Generated Health Data Technical Expert Panel convened by ONC and the National eHealth Collaborative laid the groundwork. Now we need to put those recommendations into practice!

How Do We Move Forward?

We are early in the evolution of technology support for the family caregiver. We have an opportunity to lay the foundation to improve the quality of life for 93 million people and those they care for.

But we have to be realistic about this if we are going to be successful. It’s one thing to search for information online (which 72% of family caregivers do), but another to actually find and use meaningful, relevant information technology interactively in support of care planning, treatment, and recovery.

We need people involved in this process. The emerging workforce of navigators, care and case managers is a great place to start. Why? “Because data does not mean action and technology does not mean connected care” (Gail Embt at Kinergy Health). We need the ability to communicate with our loved one’s providers, to organize and interpret information, to monitor our loved ones condition (even when we are not with them!), to coordinate care and services. A few specifics include:

- Established resources in every community for healthcare, services, and technology coordination
- Education for family caregivers on tools and technologies that can support their caregiving needs
- Re-tooling of existing medical information into plain language and multi-lingual resources that family caregivers can easily understand
- Widespread use of secure messaging technology between patients, their family caregivers, and their providers
- Blue Button capability across providers so family caregivers can aggregate the patient’s medical records and test results in one place
- Comprehensive care planning that is actionable and tailored to the needs of patients and family caregivers

Care Plan Re-defined:

An actionable plan to assist caregivers in providing and/or coordinating care for their family members – that links the healthcare, social services, and community supports needed to support them in healthcare transition, medication management, treatment and recovery.
Then, let’s aspire to get to a place where family caregivers are respected, integral members of the care team, supported by advanced health information technology. We will discuss how providers can collaborate with family caregivers to accomplish this vision in the next section.

**Culture Change: The Path Forward**

A staggering amount of culture change is needed to re-invent our current “sick care system” and replace it with a collaborative health ecosystem that is patient-and-family-caregiver-centric. We will soon have mountains of technology in place, just waiting for information to begin flowing. But if we do not address the necessary culture change in parallel with the implementation of technology, family caregivers will be left behind.

**Culture Gaps:**

For Sarah, who was suddenly thrust into the role of caregiver for her husband, the blurred lines of communication were frightening: “...our biggest challenge was when the Neurologist gave us the diagnosis and walked out of the room telling, as an afterthought, to make an appointment for another test that afternoon. I was in shock. I did not know whether to start crying or screaming. My children were young and I was pretty sure that would be Ernie’s last day of work. I felt afraid and terribly alone. There were no words of encouragement about gleaning help or time for asking questions and getting answers about Alzheimer’s disease.”

In Stan’s case, the importance of 2-way communication with his mom’s providers was driven by a language barrier. “...sometimes I had difficulty convincing my Mom’s doctors/nurses that I need to accompany her on all her appointments due to her limited English proficiency.”

Providers are at the epicenter of this shift in culture and thus the focus of the following recommendations for moving forward.

**Key Recommendations:**

**Identify the Family Caregiver in the Medical Record.**

One of the recommendations of the Commission on Long-Term Care is to identify the family caregiver in the patient’s medical record. When you consider the hats that we wear: care coordinators, medical record keepers, medical decision makers, insurance navigators, medication administrators, and deliverers of complex medical care, who better to have as a partner in the patient’s care? Allow the patient to identify their active family caregiver. This is the individual they rely on to help sort out health related issues.
Let’s take this idea a few steps further:

- Capture the family caregiver’s name and role in caring for the patient, along with their contact information
- Make this the first step in developing the patient’s care plan in which the family caregiver is a key contributor and participant
- Participate in Blue Button and help make medical information useable and accessible

Commission on Long-Term Care Recommendation:

“Family caregivers should be identified in the individual’s EHR, especially when they are a part of the care plan. With the individual’s permission, family caregivers should have full access to the patient’s records and care plan.”

Include the Family Caregiver in the Conversation and Treat Them as Key Members of the Patient’s Care Team.

Family caregivers are the people doing the “heavy lifting” behind the scenes. You likely know the engaged family caregivers in your community. They frequently call to make medical appointments and accompany their loved one to those visits or show up in the ER when a family member is in need. Are they comfortable with the care they are being asked to provide? Do they know where to find support services? Ask them.

Listen/Educate/Train: “LET” family caregivers help:

- Pay close attention to the information they have to share
- Add their observations to the patient’s medical record
- Begin a dialogue with them and enable them to reach you via secure messaging

Educate

- Refer them to resources in the community that can help support them as caregivers
- Make them aware of tools such as patient portals, Blue Button, online resources and support communities

Train

- Show them how to use your patient portal effectively
- Provide hands-on training for any medical tasks they will be performing
- Assist them in navigating the next steps in care

Family caregivers can be your greatest asset if you take the time to engage them and share information with them. For example, be proactive -- don’t assume that family caregivers know about your patient portal, how to use it effectively, or how to navigate the next steps in their loved ones’ care. This does not come naturally to most people – but it must be a skillset that we teach our population moving forward.
Redefine Care Coordination and Break Down the Silos of Healthcare, Social Services, and Community Supports.

The family caregiver definition of “care coordination” differs significantly from the traditional version, which focuses on coordination between providers.

Care coordination, in the eyes of the family caregiver, is a collaborative process that happens at the intersection of healthcare, social services, and community supports. Without all three components working seamlessly together, our jobs become much more difficult, if not impossible. In fact, social services and community supports (meals, respite care, transportation) are often more important to both the patient and the family in healthcare transition, medication management, treatment and recovery.

Moving forward:

- Identify care coordination champions in your organization
- Actively engage and partner with local organizations that can assist family caregivers, i.e. Area Agencies on Aging, Aging and Disability Resource Centers (ADRCs), Alzheimer’s Association, faith-based groups, social services, adult day centers, and many more
- Take advantage of the knowledge of your existing partners in home health or long-term care about local service providers
- Assist family caregivers in finding resources in the community that can help support them

Care coordination is truly a “community sport”! Organizations that provide these support services are eager to partner with healthcare providers. Identify a care coordination champion in your organization and start connecting the dots in your community. Leverage the knowledge of existing partners who know the social services and community supports landscape well.

Help Change Attitudes.

Make it everyone’s responsibility to assist the family caregiver in coordinating both healthcare and support services.

- Raise awareness with your staff
- Establish key person(s) within your organization to take the lead in a caregiver initiative
- Actively engage and partner with local organizations who can assist family caregivers
- Be proactive: learn about new technologies (including mobile apps) that can support family caregivers

Changing attitudes is about changing culture and we have to change attitudes across the healthcare continuum. Start by identifying a champion in your organization to spearhead a family caregiver initiative. Learn about organizations and new technologies that can support family caregivers. Encourage your colleagues to do the same.

Technology Needs a Little Help
Technology alone cannot address these challenges. It needs a little help from a re-aligned health workforce that includes patient educators, navigators, local care and services coordinators, and care/case managers, to re-engineered workflows that include:

- Capture of family caregiver information
- Collaborative health and care planning
- Education and training of the family caregiver
- Seamlessly coordinated care (including social services and community supports)
- Partnership with the community

Health information technology, in order to deliver on the promise of better healthcare, must be accompanied by people and process changes. Simply introducing the technology component and assuming that the problem will be solved is not realistic. Healthcare is complicated. We need to insert those who can help navigate, those who can educate, and those who can coordinate, into the healthcare workforce. We need collaboration among healthcare professionals, service providers, and communities on a whole new level.

**Conclusion**

We are at a critical juncture when it comes to the family caregiver, an indispensable and frequently underutilized member of the healthcare team. They need the right information at the right time in order to be effective health managers. How we enable technology to support and empower them will define the transformation of healthcare moving forward.

In addition to focusing on supportive technology, we need to embrace the culture change needed to shift the emphasis from the 10 - 15% of health that is determined by medical care delivery and the 85 - 90% of health that is determined by other factors\(^iv\), where the family caregiver often plays a key role in patient outcomes.

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\(^3\) Ibid

\(^iv\) http://www.tedmed.com/talks/show?id=47020

\(^v\) http://www.himss.org/library/NEHC

\(^vi\) http://www.healthit.gov/sites/default/files/pghi_tep_finalreport121713.pdf

