Justifying software for home caregivers.

White Paper

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Introduction

"Approximately 87% of Americans who need long-term care receive it from informal, or unpaid, caregivers." [Caregiving in the U.S. 2009 – National Alliance for Caregiving in collaboration with AARP]

"The vast majority- 80%- of elderly people receiving assistance, including many with several functional limitations, live in private homes in the community, not in institutions." [Selected Long-Term Care Statistics – Family Caregiver Alliance**]**

In other words, unpaid home caregivers shoulder most of the elder care responsibilities in the United States.

This paper presents the numbers and concepts behind the statement above. The caregivers are described in terms of their demographics and the nature of the work that they perform. (Not surprisingly, the group quietly shouldering these responsibilities lives in all of our neighborhoods.)

There are reasons to believe that the changing healthcare landscape (as reflected in the Affordable Care Act) may result in growing financial support for homecare. Specifically, the shift from fee-for-services to fee-for-outcomes, may force some recognition of the relationship between homecare and patient outcomes. The implication is that there are financial incentives to provide better homecare (along with the fact that the elderly prefer to stay in their homes).

The tools available to caregivers will be outlined followed by a description of the tools that they need.

Finally, the case will be made that Red Boat Care (www.redboatcare.com) has produced the software product that caregivers need to manage healthcare in the home.

Current homecare in the U.S.

In June of 2015, AARP released a report [i], which provided a comprehensive picture of unpaid family caregivers. This report, along with the others cited below, conveys an unpaid homecare community that is large, centered on the family [ii], expensive, and growing.

Some numbers to frame homecare in the U.S.

It is large
> "An estimated 43.5 million adults in the United States have provided unpaid care to an adult or a child in the prior 12 months."
> [2015 Report - Homecare in the U.S." AARP]

Centered on family

> "A vast majority of caregivers (85%) care for a relative or other loved one:"
> [Caregiver Statistics: Demographics]

Expensive

> "At $470 billion in 2013, the value of unpaid caregiving exceeded the value of paid home care and total Medicaid spending in the same year, and nearly matched the value of the sales of the world's largest company, Wal-Mart ($477 billion).
> [AARP Public Policy Institute. (2015). Valuing the Invaluable: 2015 Update.]"

And it is getting bigger (The population of people needing care is growing in size.)

> "In the United States, the proportion of the population aged >65 years is projected to increase from 12.4% in 2000 to 19.6% in 2030 (3)"
> [Public Health and Aging: Trends in Aging --- United States and Worldwide – CDC (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm)]

There is a clear reason to help home caregivers.

Some things to know about home caregiving

Who are the caregivers?

The following statistics are taken from the 2015 AARP Report [iii]:

- The majority of caregivers are female (60%).
- They are 49 years of age, on average.
- Eight in 10 caregivers care for just one adult (82%).
- The average duration of caregiving is 4.0 years.
- On average, caregivers spend 24.4 hours per week providing care.

Why are they unpaid? (In other words, what Medicare does not cover.)

Taken from the HHS handbook on Medicare and Home Health Care :
"If you're eligible for Medicare-covered home health care (see page 5), Medicare covers the following services if they're reasonable and necessary for the treatment of your illness or injury: …" [iv]

"… illness or injury…";

Medicare does NOT cover all the work daughters (see prior statistics) do to take care of a loved one.

"**Medicare doesn't pay for:**
- 24-hour-a-day care at home
- Meals delivered to your home
- Homemaker services like shopping, cleaning, and laundry when this is the only care you need, and when these services aren't related to your plan of care.
- Personal care given by home health aides like bathing, dressing, and using the bathroom when this is the only care you need." [iv]

To sum up, Medicare doesn't pay the costs of taking care of the elderly. There isn't any reimbursement for children wishing to support their parents "Aging in Place". For example, consider the daughter who wants to ensure that her parents are taking their medications and performing recommended activities, including personal hygiene; she will not get paid.

Also, Medicare pays for only brief periods of time to treat "illness or injury" whereas the caregiving duration is on average 4 years [i].

Medicare pays for treatment, not for care giving.

The primary caregiver and caregiver tasks

The primary caregiver is the person who assumes responsibility for a homecare recipient. The following characteristics particularly apply to primary caregivers [v].
- **Have no perceived choice.** The caregiver is often thrust into the role of caregiving when called upon by the needs of a family member. [vi][vii]
- **Have the caregiving responsibility for over four years.** [viii]
- **Perform a wide range of caregiving duties, including nursing level tasks** [iii]**:**
    - "About 6 in10 caregivers assist with medical/nursing tasks (57%)" [ix]
    - "Doing more: IADLs (Instrumental Activities of Daily Living), medical/nursing tasks without training, and all three key activities (monitoring, communicating, advocating)"
    - "A majority of caregivers help their loved one with at least one Activity of Daily Living (ADL; 59%),"
    - Of caregivers: "A majority monitor their care recipient's condition so they can adjust care accordingly (66%) and communicate with health care professionals about their recipient's care (63%)."
- **Have another job** [x] **(is typically overworked** [xi]**).**
    - "Six in 10 caregivers report being employed at some point in the past year while caregiving. Among them, 56 percent worked full time, and on average, they worked 34.7 hours a week."
    - "Six in 10 caregivers report having to make a workplace accommodation as a result of caregiving, such as cutting back on their working hours, taking a leave of absence, receiving a warning about performance or attendance, or other such impacts."

Primary caregivers and the complete medical picture

The primary caregiver is in a position to have the most complete information on the medications and prescribed regimens for the healthcare recipient. While there is hope that one day **all** of the patient's medical information will be electronically combined together, the current medical systems lack of interoperability keeps that dream distant. Each of the patient's different physicians may only have a part of the complete medical picture. The primary caregiver is in the best position to aggregate the care recipient's medical information from the various healthcare providers.

Shifting healthcare landscape and homecare

There are some changes to the healthcare landscape that have an impact on healthcare in the home.

The Affordable Care Act (ACA) of 2010 and patient outcomes

Fee-for-outcomes

A significant component of the Affordable Care Act is the shift from fee-for-services to fee-for-outcomes [xii]. Specifically, CMS is shifting how they pay for health services, from reimbursement for specific procedures to reimbursement for improved patient health (as determined through various metrics).

Hospital Readmissions Reduction Program (HRRP)

Section 3025 of the Affordable Care Act [xiii] monetarily penalizes hospitals if their patients are readmitted too soon after discharge. As a result, hospitals are starting to become more mindful of the patient discharge environment (e.g. transitional facilities that have low patient return metrics).

Homecare and Patient Outcomes

Common sense and research confirm that in addition to being preferred by patients, patient outcomes can be improved and patient costs can be reduced through effective homecare [xiv][xv][xvi].

It is not a leap to infer that effective homecare software tools will help contribute to better outcomes of homecare recipients.

Current software tools for primary caregivers

The evidence of home caregiver neglect can be seen in the limited software tools available to them. There are three categories of tools currently available.

Three-Ring Binder

To those who have lived in a world of electronic documentation, the following recommended health management approach will be difficult to embrace: the three-ring binder. From Gail Sheehy's *Passages in Caregiving* to the accounts offered in Nell Lake's *The Caregivers*, three-ring binders are recommended as a flexible and extensible way to manage caregiver information. A couple of examples are offered below:

- The Caregiver's Notebook: (http://www.springwell.com/docs/Resources/Caregiver_Notebook.pdf)
- Caregiver Notebook: http://www.ashlandmhrb.org/upload/documents/caregiver_notebook.pdf

The virtues of the three-ring binder are important to keep in mind when considering an electronic approach to healthcare record keeping, e.g. different sections for the different types of medical information, the ability to take notes, etc.

Disparate software tools

Another approach to healthcare information management is to cobble together a set of disparate software tools to address different caregiving needs. An example of this is reflected in the following AARP post: *9 Need-to-Know Technologies for Caregivers* (http://blog.aarp.org/2012/04/26/sally-abrahms-caregiving-technology-must-haves/). Several different software tools are offered to help with essential caregiving **"**Medication management" and "Care Coordination" tasks.

The post above underscores the types of healthcare tasks that need to be managed in the home. There are some obvious advantages to having the medication management activities be connected to care coordination activities. In other words, there are advantages to having these capabilities reside within a single tool.

Tools for Institutional Caregiving

A search for "software for caregivers" will return several established products. These products tend to focus on the needs of institutional caregiving, e.g. agencies that provide caregivers who go into the home for a fee. A large focus of these tools centers on the management of staff and client accounts.

Caregiving agencies have billing and payroll requirements: they must bill their clients and pay their caregivers. Quite appropriately, agencies logically seek software that features these billing and payroll capabilities.

An additional consideration they may have is the management of those tasks that are subject to CMS reimbursement.

Managing agency clients
- Caregiving agencies are focused on servicing client requests.
    - Learning and documenting caregiving requirements.
    - Logging caregiving activities.
    - Billing clients for caregiving activities.

Managing agency caregivers
- A primary consideration for caregiver agency software tools is the management of caregivers. Three of the capabilities required for caregiver management are:
    - Scheduling caregiver hours.
    - Logging caregiving activities.
    - Tracking caregiver hours and payroll.

Servicing the silos of Medicare/Medicaid funding & reimbursable activities.
- Medicare/Medicaid has specific definitions of what types of services can and cannot be reimbursed. The services offered by caregiving agencies may be influenced by these constraints.
- The software used by agencies subject to CMS constraints may also reflect the same restrictions.

What primary caregivers require:

Coordinating the village that it takes [xvii]

Human beings do not come with operating manuals included. Few of us are prepared for the realities of the responsibility of taking care of an aging parent.

The challenge of taking care of someone can be very demanding, especially when more medications and medical personnel become involved. This insidiously increasing burden of caregiving often exacts a health toll on the primary caregiver [xviii]. When this happens, the long-term success of caregiving depends on getting extra help (i.e. the enlistment of a caregiving team) [xix]. Enabling a healthcare team requires a new level of communication and coordination capabilities.

Managing home care: Answering the Five W's

The first order of business in managing healthcare is to simply know what needed to be done and who was going to it. That idea inspires the answering the "Five W's" [xx].

Who
The primary caregiver must know appropriate information for all of the healthcare team members:
- The care recipient (typically a family member).

- The family (sisters and brothers etc).
- The caregivers (both professional and non-professional).
- The care providers (physicians, therapists, etc).
- The other care participants (pharmacies, supply houses, etc.)

What

The primary caregiver must know the care recipient's healthcare information:
- What medication **must be taken**; what activity must be performed; what appointment must be met.
- What medication **has been taken**; activity performed; appointment met.
- What are the issues with taking a medication or performing an activity.
- What are the vitals of the care recipient; allergies; etc.
- What does the care recipient like for lunch; what sports teams or ballets do they like.
- What should be done in case of an emergency.

When

The primary caregiver must know various scheduling times:
- When does a medication need to be taken; activity performed; appointment met.
- When was the medication taken; activity performed; appointment met.
- When are caregivers scheduled to arrive: today, tomorrow, next week.
- When was the last immunization given.

Where

The primary caregiving that is done in the home.

Why

The "why" of healthcare can take many forms:
- Why is the medication being taken or why was it discontinued?
- Why do several medications need to be taken at the same time?
- Why is a caregiver needed at 7:00 o'clock in the morning?
- Why does the person receiving care need to be outside at lunchtime?

Managing a home care tool: The How

How (to create a successful, care management, software tool)

The key to creating this successful product design is to understand what caregivers need to do and how they need to do it. Merely presenting them with healthcare information is insufficient. The tool must respect the relative priority of tasks and present them that way. (For example: Upon arriving at the patients' home, the caregiver will need to know what tasks have been performed and what tasks are yet to be performed. Knowing when an immunization was given is important, but it is typically not the first thing a caregiver thinks about.)

Product designers use the following standard methods to create effective products:

- Analyze workflows. (Study what and how caregivers do their work.) The goal is to make sure that everyday tasks are easy to understand and perform.
- Follow user interface principals and practices.
- Make sure that information is securely available anytime and from anywhere.
- Iterate (keep learning, keep improving).

Red Boat Care

Tools for the primary caregiver in the home

Red Boat Care (RBC) is a company that was founded to provide software tools for caregivers. RBC's goal is to focus on the needs of the primary home caregiver and the needs of the person receiving care.

RBC has produced a software product that allows the primary caregiver to coordinate and communicate healthcare goals with the caregiving team. RBC's Medical Activity Planner (MAP) provides secure access to the medical information at any time, from any place, on any web browser. Furthermore, family members can track the progress of the person receiving care.

Conclusion

The time is right for effective software tools for primary caregivers

It Is Needed

Primary caregivers need a tool to more easily manage the complexities of healthcare.

It Is Timely

Primary caregivers need Red Boat Care homecare management software now. They need this record-keeping software that will both assist the caregiver and structure the design of outcome-based healthcare in the home.

It Is The Right Thing To Do

Helping primary home caregivers is a good thing. It needs to be done. Red Boat Care has done it.

References

(i) "2015 Report - Homecare in the U.S." AARP

(ii) "A large majority of caregivers provide care for a relative (85%) Caregiving in the U.S." (2015) AARP

(iii) Caregiving in the U.S. (2015) AARP

(iv) Medicare and Home Health Care – HHS (https://www.medicare.gov/Pubs/pdf/10969.pdf)

(v) "Over six in 10 caregivers perceive themselves to be the primary unpaid caregiver, meaning either that they are sole caregivers (47%) or that there are other unpaid caregivers, but they themselves provide the majority of unpaid care (16%). " Caregiving in the U.S. (2015) AARP

(vi) "When asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers self-reported they had no choice in taking on their caregiving responsibilities." Caregiving in the U.S. (2015) AARP

(vii) "Over half of those who feel they had no choice in taking on their caregiving role report high levels of emotional stress (53%)." Caregiving in the U.S. (2015) AARP

(viii) "Primary caregivers have been in their role longer than nonprimary caregivers (4.6 years vs. 2.8 years, on average)." Caregiving in the U.S. (2015) AARP

(ix) "About 6 in10 caregivers assist with medical/nursing tasks (57%)" Caregiving in the U.S. (2015) AARP

(x) "Sixty percent of caregivers were employed at some point in the past year while also caregiving." Caregiving in the U.S. (2015) AARP

(xi) Caregivers Sometimes Must Sacrifice Their Careers – Paula Span - New York Times (http://www.nytimes.com/2015/12/08/health/elder-caregivers-often-sacrifice-their-careers.html?_r=0.)

(xii) Better, Smarter, Healthier: In historic announcement, HHS sets clear goals and timeline for shifting Medicare reimbursements from volume to value – HHS.gov (http://www.hhs.gov/about/news/2015/01/26/better-smarter-healthier-in-historic-announcement-hhs-sets-clear-goals-and-timeline-for-shifting-medicare-reimbursements-from-volume-to-value.html#)

(xiii) Section 3025 of the Affordable Care Act

(xiv) "Not only can care be provided less expensively in the home, evidence suggests that home care is a key step toward achieving optimal health outcomes for many patients." – Home – The Best Place for Health Care. – The Joint Commission (http://www.jointcommission.org)

(xv) Improving patient outcomes with better care transitions: the role for home health. NCBI Cleve Clin J Med. 2013 Jan

(xvi) "The Future of Home Health Care Project" (http://www.ahhqi.org/images/pdf/future-whitepaper.pdf)

(xvii) "About half of all caregivers report that someone else has also provided unpaid care to their care recipient over the past year." Caregiving in the U.S. (2015) AARP

(xviii) Caregiver Health - Family Caregiver Alliance (https://www.caregiver.org/caregiver-health)

(xix)   "Only about half of caregivers say another unpaid caregiver helps their recipient (53%). " Said another way, most caregivers have the help from another caregiver. Caregiving in the U.S. (2015) AARP

(xx)   Wikipedia (https://en.wikipedia.org/wiki/Five_Ws)