The Complex Business of Health Care and Caregiving

In today's world, the complexity of conducting personal business is continually growing. When choosing health care services and products, complexity can result in poor decisions that adversely affect health, financial wellbeing or both.

Understanding and coordinating healthcare services and coverage benefits is most needed when one's health is poor or at risk. However, when people are sick and experiencing physical and emotional stress, they often fall prey to poorly coordinated care among providers, omissions and errors due to poor communication, reduced access to care and a higher personal out-of-pocket expense than necessary.

This paper explores the causes and challenges of the growing complexity surrounding health care and caregiving.

To begin our exploration of the problem, we will first consider three examples of personal business we conduct outside of health care, and the detailed information, comprehension and language required for someone to make informed and good decisions. Many people would benefit from a course on these topics to help them avoid missteps that make them worse off.

1. In general, employers no longer promise retirement pensions. The onus for saving and investing for retirement now falls on the worker. Workers now must make self-directed investments in 401(k) plans and other retirement accounts. This makes understanding stocks, bonds and the capital markets important for middle- and working-class America.
2. Buying and owning a house has become very commonplace; about two thirds of American households are owner-occupied.[1] This makes it important for most consumers to gain an understanding of types of mortgages, how they are sold and priced, and how our personal credit histories are established and scrutinized by lenders.
3. The number and types of college degrees and college institutions have increased so much that it is often confusing for a prospective student, young or old, to discern what curriculum will yield more personal satisfaction and future wages at a reasonable cost. Additionally, there is the maze of obtaining college financial aid and student loans.

Self-perpetuating markets and regulatory systems drive the continued evolution of each of these complex ways of addressing savings, housing and educational needs.

Self-fulfilling forces and trends similarly affect the process of choosing, accessing, using and paying for healthcare products and services. Major forces and trends include:

1. Mass media communication
2. Internet communication
3. Massive databases
4. Medical meccas
5. Expectations of high quality health care paid for by health benefit and entitlement programs
6. Liberal use of medical technology to preserve and prolong life
7. Voter support for both large government health benefit programs and free market methods that allow physician and patient to influence treatment
8. Societal acceptance of a lack of price and cost transparency as normal

[1] National Multi Housing Council. Quick Facts: Resident Demographics. Last accessed April 4, 2013: http://www.nmhc.org/Content.cfm?ItemNumber=55508.

Anxiety and Family Dynamics Compound Difficulties

The desire to be well and experience quality of life, along with the reality of dying, are why we use doctors, hospitals, nurses and therapists. Personal anxiety and questions regarding health, dying and relationships all exist naturally. Interacting with a complicated and fragmented healthcare benefit system often creates an additional layer of anxiety.

Consider the common tensions of parent-child or spousal relationships. When one is or becomes a caregiver, these family dynamics may be fraught with resentment and distrust, adding a layer of personal stress and emotion.

American society has created a difficult-to-navigate healthcare system. Often, each hospital, physician, laboratory, pharmacy and home care entity a patient uses is a separate business which does not communicate well with the others. It is fair to describe the system we have as fragmented and often confusing.

Much responsibility ultimately lies with the patient and family to coordinate the best combination of services and to understand reimbursement for the care. Even highly educated consumers struggle to understand the billing arrangements. The resulting frustration and time demands mean that many people simply do not reconcile insurer notices and medical bills which may be rife with errors in favor of the healthcare providers.

Consider a young adult faced with helping a parent make arrangements for long-term care services in the parent's home. Suddenly the child needs to know many details. What kind of home health or care agency should be contacted? What kind of reimbursement will the agency accept? What kind of private and government benefits does the parent have? How does one become eligible for those benefits, and how do you do that without risking ineligibility and assets? What missteps need to be avoided that will trigger ineligibility?

This reimbursement oriented information is just the beginning of what a caregiver should optimally know. Medical history, prescription drug lists (including the reason for each medication), allergies of various types, personal preferences, and more are needed to effectively organize and coordinate care. Lack of knowledge may negatively affect quality of care and create unnecessary caregiving and financial hardship for a family.

Decisions about Income and Assets Affect Health Benefits

Many aspects of personal finance may have an effect on healthcare benefits. A variety of government health benefits and entitlements have impacts on one another. Many misperceptions exist about who can use which benefits.

Consider a simple example. A new widow continued receiving her social security check based on her own work history. She had never filed for her spouse's benefit even though it was higher. Now, she could file for her widow's benefit based on her

deceased husband's much more lucrative earnings history. She received $800 per month based on her own work history.

With her low income, the government subsidized her Medicare Part-B and Part-D premiums. She received food stamps and lived in low-income housing. The housing was located where there was good public transportation and easy access to a senior center with good activity programming one-mile away.

Her daughter suggested she should take her widow's benefit. She began to receive $250 more per month, but suddenly she was no longer eligible for some benefits and others were reduced. Her rent increased by the amount of the check increase.

Another not uncommon story concerns veterans' benefits. A veteran was advised by an insurance agent to purchase an annuity in the form of a monthly cash payment in exchange for some cash savings. He was told by the agent that it would not affect any benefits he was eligible to receive. He and his wife also had another $100,000 in their local bank.[2]

A year later, the veteran needed to go live in an assisted living community for a cost of $2,500 per month. He learned that the annuity payment was just enough additional income to prevent his eligibility to receive help from the Veterans Administration in paying for his care at the assisted living community. The $100,000 in savings probably would not have interfered with his eligibility if the life expectancies of the veteran and his wife were long enough to justify keeping the savings.

Many people can more optimally combine the use of Medicaid; Medicare; Social Security disability and retirement benefits; veterans and military benefits; and private health plans. Middle class families often miss out on opportunities to use benefit programs because their rules are so numerous.

Sometimes the opportunity is very simple. For example, a retired spouse over age 65 remained on the working spouse's employer group insurance plan. In addition, the retired spouse was enrolled in Medicare Part-A which covers hospitalization and Medicare Part-B because his health was not good. The retired spouse anticipated surgery which fell out of the group plan network so that the hospital and physician coinsurance payments were large. His enrollment in Medicare Part-B (which he could have delayed) paid the out-of-network coinsurance charges from the multiple physician charges he incurred during the hospitalization and post operatively at home.[3]

[2] The Veterans Administration accredits attorneys and others to give advice about claiming benefits. These accredited attorneys and claims agents may be found in not-for-profit, for-profit and government entities.

[3] When the employer has 100 or more employees, the group plan pays first and Medicare pays second.

Eldercare and Elder Law

Eldercare often requires the involvement of several or many people to help address the caregiving and personal business needs of an individual. Friends, family, and healthcare providers have much to communicate to one another. Sometimes, the family does not know the medical, healthcare billing, financial or legal terminology to use in asking for what is needed, or to be able to discuss the situation well.

Elder law attorneys[4] may positively contribute to better use of health benefits, entitlements, income and assets. Some financial planners may also positively contribute, but their work should be done as part of a team of advisors serving a client. An effective team could include an elder law attorney; a tax advisor;[5] a financial planner or advisor;[6] a social worker or nurse case manager; a trusted family member or friend; and, of course, the client.

The most basic elder law legal package may include a will, power of attorney document, healthcare power of attorney document, healthcare directive, HIPAA Authorization for Release of Medical Information and perhaps a letter prescribing what is to be done with the person's remains upon death.

Middle class and affluent families may benefit from more nuanced planning to help them gain access to government benefit programs such as Medicaid. Some Medicaid programs use medical need, as opposed to financial need, for their primary test of eligibility. Not knowing this, many people may not attempt to access these programs, or they access the program only after unnecessarily forfeiting certain assets that a spouse, for example, might truly need.

Complicating the issue of government benefit programs further is the fact that Medicaid is administered on the state level alongside a number of state-specific benefits that many perceive to be part of the Medicaid program. For that reason, guidance and legal advice needs to be state-specific relative to estate, elder care and government benefit programs.

Elder Law versus Estate Planning Attorneys

Estate plans may incorporate some of the same asset protection measures that elder law may employ. However, a good estate planning attorney is not necessarily a good elder law attorney. Middle class families desiring to protect assets from long-

[4] An elder law attorney for this purpose has proficiency in estate planning but in the context of using and accessing various government and private health benefits and entitlements while sometimes protecting assets and income. There are other elder law experts that focus on other issues such as nursing home abuse.

[5] A tax advisor is often a CPA but may be a tax attorney.

[6] The two most recognized and respected designations for financial planners are the Chartered Financial Consultant and the CERTIFIED FINANCIAL PLANNER™ designations. Many other designations are much less rigorous. The Chartered Financial Analyst designation is probably the most rigorous investment oriented designation.

term care expenses should rely on those with an intimate knowledge of the interdependencies of many aspects of personal wealth and health care. Those aspects include income, assets, private insurance, investments, real estate, legal titling, transactions, private insurance coverage, Medicaid, Medicare, social security, Veterans benefits and so forth.

All wills and power of attorney documents are not equivalent. If these documents are crafted in a way that is not consistent with the assets, income and benefit strategies under consideration, the documents can be limiting if not counterproductive.

From Home Economics to Life Economics

In the 1980s and 1990s, the Home Economics curriculum began to disappear from high schools and colleges. The courses faded into history because they were associated with women serving only in a domestic capacity.

High schools, community colleges and universities have never replaced the Home Economics curriculum with one focused on other practical aspects of life such as health care and financial fluency. Detailed knowledge and comprehension is required to conduct personal business both in and outside of the home. Creating such a curriculum could have been a natural progression from Home Economics to Life Economics. Extension Offices continue to teach much of this basic curriculum.

From Child Rearing to Caring for Adults at Home

In 2009 the US Population was about 305 million, and there were approximately 115 million households. In the same year, 11.8 million people (about 4% of the population) had long-term care needs.

Of the 11.8 million people needing long-term care, 10 million resided in the community. So on average about 9 out of 100 homes had at least one resident needing help with long-term care during the year. These care needs could be as simple as help with meals or as demanding as help with bathing, dressing and toileting each day.[7]

An aging population, low birth rates and increased participation of women in the workforce has increased the demand for teaching personal care skills used in residential care communities serving the elderly. According to the U.S. Department of Labor Bureau of Labor Statistics, the number of people employed as nursing aides will increase by 20% between 2010 and 2020.

Residential care communities serving the elderly with long-term care needs employ almost 60% of nursing aides. While teaching hands-on caregiving skills gives people the skills to do the hands-on work of personal care, it does little to address the need to understand how to plan, arrange for and pay for long-term care in the home.

[7] Health Affairs Health Policy Brief: May 12, 2011.

The Economics of Dementia

A recent study of elderly adults with dementia in the U.S. provided staggering figures. The study in-part summarizes the growing healthcare burden on unpaid family caregivers as opposed to compensated caregivers such as a nurse assistant working a nursing home or a family's personal residence. [8]

The study estimated the annual cost of caring for a dementia patient to be somewhere between $41,000 and $57,000 annually, with much of that care being provided by family and friends in an in-home setting. For the U.S., the overall yearly financial burden translates to $159-$215 billion. This is at least as large as the size of the annual economic production for the state of Kentucky during 2010.[9]

About 30% of the total cost is due to lost wages. However, if this same caregiving were valued by the cost of paying in-home nursing assistants and others through employers, the care provided by families and friends would represent almost half the total financial cost of dementia to society. This cost is expected to increase by 80% by 2040.

Summarizing the Problem

To the average person the way hospitals, residential communities, doctors, pharmacies and nursing agencies collect their payments is poorly understood. Likewise the manner in which health and disability entitlements and insurance plans work and coordinate is poorly understood. Meanwhile, healthcare costs, particularly for our aging population, are increasing at an alarming rate. American society remains largely unprepared for this future cost. All of these factors accentuate the need to help people acquire the skills to understand and manage the complexity of their personal healthcare affairs.

[8] Hurd, Michael D., Ph.D. et al, "Monetary Costs of Dementia in the United States." *New England Journal of Medicine*, 368:1326-1334, April 4, 2013.

[9] http://econpost.com/kentuckyeconomy/kentucky-gdp-size-rank. Last Accessed May 1, 2013.

Virginia Clay

About the Author

The author of this expository on the complexities of health care and caregiving is Virginia Clay, a CERTFIED FINANCIAL PLANNER™ Professional and Registered Nurse (RN). Virginia received an MSc in Healthcare Policy and Management from Harvard School of Public Health, and a Doctor of Pharmacy degree from Campbell University. She has two decades of healthcare, business and personal finance experience.

In 2012, Virginia Clay founded the Living and Care Giving Project (LCG Project), a publication and education service of Blackwood Administrative and Consulting Services, Inc. The purpose of the LCG Project is to help families better coordinate and use healthcare, financial, governmental, professional and community resources. The goal is to temper the flood of emotion and influx of information with understanding and insight. The result can be a comprehensive plan that is compassionate, prudent and effective. See www.lcgproject.com for more information.