Special Issue: Aging - It’s Personal: Forum

The Unprepared Caregiver

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Abstract

Years of studying health care financing and delivery does not prepare you for the actuality of dealing with a serious health event. The practical challenges of our extremely fragmented and complex health care system make it difficult to navigate this world—even when someone is there to help the patient. And, being a caregiver is a far cry from being a health care analyst. There are many lessons to be learned for improving our system: the need for skilled co-ordination support, the need for simplifying and re-orienting the various silos of postacute care, the importance of generating ways to support caregivers, and not least, promoting simple lessons in civility for providers of services.

Keywords: Postacute care, Stroke, Medicare, Co-ordination of care

The role of caregiver is an extremely important and challenging undertaking—and one that most of us are not fully prepared to undertake. Although having a background in health can help at the margins, it is instructive and sobering to interact with the system in an up close and personal way. When my husband suffered a stroke 18 months ago, we faced a broad array of challenges in dealing with both the formal health care system and the new roles we were playing as patient and caregiver. But now with a little bit of distance, I hope to share some insights and lessons learned that might help others in similar situations and/or suggest some new directions for policy thinking.

In the summer of 2014, my husband and I were beginning to get things in order to enjoy our retirement; he was no longer employed but still very active as a writer of books, and I had been planning to phase into retirement. But in September, everything was suddenly put on hold. A stroke to the left occipital lobe left my husband with vision loss, memory problems, and an inability to read. As his sole caregiver, I found myself plunged into a confusing world of poorly co-ordinated care, confusing systems, and an expectation that the caregiver could take on full-time responsibilities. As an aging researcher of more than 30 years, I have focused extensively on Medicare and long-term care issues, so I should have been prepared. But studying issues from the perspective of how to improve overall policy is very different than trying to do the applications required. I probably was more prepared than most but still found many confusing and frustrating challenges along the way.

The U.S. health care system essentially assumes that unless a person is fully unable to function, someone else—usually a spouse or close relative—will be available to perform innumerable activities: co-ordination of care, making decisions about appropriateness of providers, performing skilled therapy and related tasks, dealing with payments, and keeping the rest of life at bay. Most of these activities are outside the purview of any insurance protection, and without these informal supports, the costs of health care would be much greater (Chari, Engberg, Ray, and Mehrotra, 2015; Donelan et al., 2002; Levine, Halper, Peist, & Gould, 2010). And the demographic changes ahead suggest that this issue will only rise in importance (Congressional Budget Office, 2013).

Caregiving is a supremely lonely experience and one which is taxing on even the most able and energetic person. I also became aware of how lucky we were to have resources and my time to fill in the many gaps in care—but even that has its limitations. One can find a lot of advice about short-term illnesses or end of life care, but much less
is written about the serious health condition that takes a year or more of your life but for which the outcome is potentially positive. The challenges are many and often surprising. How do you keep pushing for positive results and improvements over an extended period of time?

The Nature of the Challenge

Many complicated long-term illnesses have their own specific issues and likely similarities with our experience, but I am speaking in the context of dealing with stroke. It is a particularly nasty problem because it seems to be unique to each individual, and many of the general treatments and recommendations just don’t always apply. At no stage in the process, did we ever have anyone really provide a useful, realistic picture of the things to look out for, the likely areas of setbacks, or even the most productive treatments. The closest explanation that made sense to me came just several months ago from Douglas’ optometrist who indicated that although scientists understand what parts of the brain do what types of things, no two patients have the same symptoms even if the damage is in exactly the same area of the brain. She explained that everyone learns differently all their lives, so the pathways and specifics are naturally going to vary. That was about the most coherent explanation I have heard despite talking to numerous specialists. One particularly vexing problem has been my husband’s inability to read. He can write, spell, carry on a sophisticated conversation, but initially he was unable to make sense of any letters or numbers. He is getting better—but it is slow going because the first letter of each word remains a mystery to him. No one, it seems, has ever heard of this specific issue, so no one has any concept of how to address it. Much of the literature on stroke is pretty general when in reality each patient faces very different challenges.

In addition to the inability to read, Douglas’ short-term memory was severely compromised and for months he was not able to keep instructions with multiple steps or the details of his daily schedule straight (and because of his inability to read, writing down the instructions is not an option). Being a diabetic who needs to test his blood never be underestimated, and consequently, it is difficult to determine how much more formal care is warranted.

Care System

The fragmentation of the health care system should never be underestimated, and consequently, it is difficult to navigate successfully. For example, the usual progression for a stroke victim (and for other patients where an inpatient hospital stay needs to have considerable follow-up care for the patient to recover) is inpatient hospital, inpatient rehabilitation hospital, home health care, and then outpatient therapy (Rao et al., 2009). Each stage occurs in different settings and is managed by different organizations with almost no co-ordination or even knowledge from one setting to another. Even when the same overarching institution is presumably involved, each handoff occurs with uncertainty and almost no sense of how one set of services helps or informs the next set. Technically, discharge

The Good, the Bad, and the Ugly of the Health Care System

A key activity of any caregiver is to serve as a navigator for dealing with the system and ensuring that the patient gets needed care. But there are many challenges in the way our system operates that place barriers in the way of successful caregiving. Even though I have studied the Medicare program for many years, this was an enormous undertaking. When the practical meets the theoretical, look out.

Co-ordination of Care

One of the basic tenets of improving the health care system is to co-ordinate the care that is received in different settings and by different providers (Anderson & Knickman, 2001; Komisar & Feder, 2011). Certainly this is crucial—but, in practice, we are a long way from that ideal in the traditional fee-for-service setting (which is where we have been operating; Osborn, Moulds, Squires, Doty, & Anderson, 2014). And, often more integrated systems have problems as well (Grabowski, 2012). Once beyond what Medicare traditionally covers in the way of therapy, one is left on your own to determine how much more formal care is warranted.

The very good news is that except for the peripheral vision, most of these challenges have lessened and will continue to improve over time. But it means developing a whole new sense of what one gets pleasure from and how to interact with others. It means striking out on our own because much of the literature focuses on early recovery (Rao, Conroy, & Baron, 2009). Many of these challenges are beyond the capabilities of the health care system, although there are still important lessons we have learned the hard way. It is my hope that sharing some of these lessons may help others and will certainly affect my approach to policy analysis and advocacy in the future.
planning is offered and even required at various stages, but it can consist of as little as handing the family a list of eligible providers in an area with no supporting information or documentation. Research tells us that we don’t want health providers steering people to their own agencies or best friends (Medicare Payment Advisory Commission, 2009), but there needs to be a better way of providing decision making information without having that become the midnight to 1 am search activity by an exhausted caregiver.

In the fee-for-service world, each patient or caregiver is their own general contractor: making appointments, cajoling providers at different levels to communicate, and even deciding what the next steps will be. Many of the specialists are skeptical of each other’s skills and seem to be in competition. Each different setting has a different set of rules and requirements. And particularly toward the end of acute care treatment, it becomes less and less clear what is next and what further progress should be expected.

At the end of the progression noted earlier, the care essentially ends with a whimper. Outpatient therapy under Medicare has an arbitrary annual dollar limit (adopted purely for reasons of budgetary savings) and once that is reached, care ends. In Douglas’ case, that was in the spring of 2015. He was nowhere nearly recovered, but perhaps even more important, because these courses of home health and then outpatient therapy are always quite short, the actual activities seem to have become rather prescribed—almost rote. So, for example, here is someone unable to read numbers or to retain multiple-step instructions being pushed by the home health aide to re-learn how to dial the telephone. What about assistive technology that could bypass some of that? No mention; instead the young therapist was increasingly frustrated by his difficulty in mastering this task and passed that frustration on to Douglas. Similarly, at the end of the outpatient therapy, two full sessions were devoted to teaching Douglas how to use an electric kettle to make rice and tea—activities that he never undertook before the stroke and has no interest in doing. But this seems to have been part of the playbook even though the individual had worked with him over a period of weeks and could have adopted a more useful set of activities. Care for Douglas paid by insurance largely ended after about 7 months—although the literature suggests that recovery from stroke goes on for much longer (Rao et al., 2009).

Some researchers have suggested adding a care co-ordination specialist to the mix and that might be helpful, but it would be important to have that person follow the patient rather than be housed in just one setting (Moon, Hollin, Nicholas, Schoen, & Davis, 2015). And then who would co-ordinate and oversee the co-ordinators? How would they be accessed—or compensated? At the moment, such activities are largely small scale, cottage industries with little formal attention or support (Stone & Harahan, 2009; Kaye, Harrington, & LaPlante, 2010). And the services are only available to those who can afford to pay out of pocket.

One answer might be to rely upon a system in which one organization provides all of the necessary care at each stage of the process. Integrated health care systems promise that they will manage the handoffs and see that the care is seamless. It does not always work that way in practice either, however. In one turnaround handoff, it seemed the best approach would be to work with the home health agency affiliated with the rehab facility. But in this case, there was no co-ordination and hence no advantage of using related entities. In fact, after only a week I “fired” the home health agency. After a brief orientation, it was our responsibility to call all the individual aides to set up appointments; the nurse finally called back after 2 weeks (and 1 week after I informed the agency that I was going elsewhere) and said she was ready to meet with us. That is, a homebound, very sick patient in a “co-ordinated” situation was not going to be treated for over 2 weeks—an outcome that as a Medicare researcher, I was shocked to learn. Fee for service gave us the option to find another provider—something that would not happen in a managed care environment where we would have to use the designated agency.

Our second experience with home health was more successful—but only because I used personal connections. None of the information on quality or availability indicated anything about actual access to services and timeliness of care; someone without a network of professional friends would have been hard-pressed to figure out what to do. Special attention to this so-called postacute care environment is needed. New proposals, such as “bundling” postacute care, are supposed to help but will largely focus on saving costs to the Medicare program (Naylor et al., 2012).

Making Decisions

As health care has become more complicated and fragmented, consumers of care are increasingly responsible for making good choices and even managing what happens at various stages of treatment. Consequently, a great deal of research has gone into not only measuring quality and good practice but also in developing materials that consumers can use in decision making (Carman et al., 2012). But, practical advice at the time of need is hard to come by.

Information seeking is also complicated by timing. Most of us are “just in time” users of information—seeking advice while in the throes of our complex and fragmented system. That makes obtaining information—and being able to act on it in a timely fashion very challenging. In my experience, each time there was to be a handoff to another setting, I would be reassured that I had several days to make arrangements—but then the timing would shift and it was “make a decision right now.” Using quality information that is supposed to help with these decisions is difficult to access and understand when you are under the stress of both a deadline and the general worry over being the caregiver for someone who is very ill. More needs to be done to empower consumers and ensure that the tools that have
been developed get used. Moreover, some of the practical questions about availability of providers in a high demand environment would be helpful.

Providers of care should also be knowledgeable about the quality and rating information available and have copies of such materials to share. This is one of the missing links that occurs in the health care decision making process. Busy professionals in one setting have little knowledge of how the other settings operate, and hence they cannot offer much guidance. This is particularly a problem when a continuum of care is needed—such as rehabilitation and therapy providers who provide some services but then shift patients to others for follow-up. Materials developed need to make sense not only to patients but also to the providers of care, or they will not be used. Some research done several years ago found that health care professionals and consumers often talk past each other: they are looking for different things and often express very different reasons for ignoring quality information, for example. Getting them on the same page can be challenging.

In only four cases of the 18 institutions or providers we dealt with over the past 18 months were written instructions or summaries of care provided. Even though many of the providers use electronic records and it would be possible to provide written materials rather simply (Hillstead et al., 2005) (and for which we have one good example where that happened), most send you on your way after a rather rapid fire set of instructions and information. And even the “good” example still left a lot of unanswered questions. The worst case situation was a specialist who not only provided very cursory information with lots of confusing jargon—he did so in his busy waiting room, which is a clear violation of privacy requirements (so-called HIPAA regulations referring to the Health Insurance Portability and Accountability Act rules). In that case, we were able to get some additional information when another physician shared with us the letter he received from the specialist about my husband. But who should one complain to about this outrageous behavior? None of my health policy friends could offer good suggestions.

**Taking the Time to Interact**

Perhaps the most disappointing aspect of care is the unpredictable and often impersonal nature of interactions with providers. Most of the professionals we dealt with were clearly competent and provided the necessary services. But just a little additional effort makes an enormous difference in what happens. One of the worst situations was a nurse who on the second night of Douglas’ hospital stay, when he was extremely confused and delirious not only from the stroke but also from a prescription drug problem, suggested to me that “he might get better.” I was extremely distraught and exhausted but even then I knew that his prognosis was much better than that. She would not have been giving me false hope; instead, she was extremely negative when some positive encouragement could have helped a lot. In the same hospital we had another, opposite experience of extraordinary effort by a young hospitalist who took the time to look at the full range of issues Douglas was facing (including doing extra research) and who also spent time with him when he was very confused, talking to him, and reassuring him while fending off the specialists who simply wanted to run another battery of tests. We were fortunate to have him managing Douglas’ care for 6 days. On paper, it would not seem that that care was extraordinary; it simply was the case that he went the extra mile. Sadly, I am at a loss of how to suggest we encourage or reward providers for such behavior—or how we can successfully build that in to quality reporting. The survey we received to fill out after the hospital visit was totally inadequate for such a purpose—something that I was surprised to discover.

**Caregiving**

When someone goes through a serious illness such as a stroke, there is so much care needed beyond the strictly medical activities. Caregiving involves a whole range of activities, largely filling in for all the care that the system “assumes” someone else will do such as administering medication, providing basic support and hygiene, and sometimes providing transportation and other basic supports—services that can and often are provided by outsiders when the patient is covered by Medicaid or has the ability to privately pay for such services. A vast literature is available in this area, including Doty (2010), Stone and Harahan (2010), and Wolff and Kasper (2006) and Kaye et al. (2010). These long-term care needs are pretty straightforward. But in addition, the patient needs someone to coordinate all of the formal and informal care, an advocate in dealing with providers, a bill payer, and a companion who can provide emotional and intellectual support. This latter is perhaps the most crucial for someone who has lost some capacity—even if only temporarily—and who is scared and frustrated by these changes. Adjustment to a “new normal” is not something that is easily delegated to others.

In many ways, we were fortunate; I have had the resources and time to fill this role. But not everyone is so lucky. Indeed, one of my greatest fears is what would happen if I had a similar problem and we both had to depend on a third party. As people who have always lived independently and have no children or other close relatives, it is a terrifying prospect. Who will care for either of us if we are truly alone? My next biggest task is to redo our wills and try to figure out who we could each rely upon if not for each other. This is beyond what people often consider in thinking about living wills and durable powers of attorney and suggests the need for more detailed instructions in some cases.

And although I believe I have done a good job at being a caregiver, the fear is that it is never enough. And then there is the guilt that arises when one’s instinct now and then is to run off and join the circus—or go anywhere else. Why
can’t we just go back to the way it was? How long will the “new normal” last? What do we accept as permanent and what do we keep struggling with? Finally, there is the loneliness of being a caregiver: There is not enough time to reach out to others particularly when things seem like they are closing in. Sometimes you are not even sure about what you want and how to go about getting it (Lyons, Cauley, & Fredman, 2015). How much time should you spend looking for help versus just doing it yourself? How do you find workers you can trust? Agencies are often very casual about sending out different people so you don’t develop much of a relationship, and going out on your own to hire workers is difficult and risky.

In my case, I work for an employer who offers generous wage replacement so I could continue working—maintaining relationships and a base of normalcy—but also having time off for caregiving. For many people this would not be an option, affecting both financial resources and the advantages of keeping part of one’s environment stable. Some expansion of paid family leave requirements could be very helpful here (Chen, 2014). One challenge that remained, however, is that working while caregiving means that work colleagues need to be flexible as well. Even long-held plans may need to change when health crises arise. Some colleagues—even in the health care world—often find that a difficult concept to put into practice.

Easy solutions to the challenges of caregiving are hard to come by. This is likely an area in which any solution must offer maximum flexibility because every situation is going to be different. But a first issue that must be grappled with as people concerned with aging issues is the basic assumption that our whole system is predicated on the notion that there is always a caregiver available for patients. What do we do when that is not the case? Institutional care is surely not the answer especially for patients who should be able to recover with a little extra effort. Some additional structure and support is needed to make the market for informal caregivers work better. Agencies that mark up the cost of care by 100% are not the only answer. But the individual market needs help. Places like Care.com provide some clearinghouse support, but winnowing down the potential list of workers and finding a good match are extremely time consuming. Better ways to sort the market and provide a little more structure would be very helpful, but it is important to also guard again too much bureaucracy. States that allow Medicaid recipients to hire their own workers could help provide such a structure for those not eligible for Medicaid as well, for example, but states vary in terms of how active they are in providing oversight (Doty, Mahoney, & Sciegaj, 2010). Protections for those who need support services and for those who provide it are important to make the market work better. How do we assess quality? How can people figure out the system to make it work well? How can billing be simplified and improved to reduce that burden? Surprise bills after more than a year has passed—and the rigidity of supplemental insurers to Medicare to deal with complications—lead to the patient bearing extra costs just to avoid spending any more time on the problem.

At least some scaled down support would be extremely helpful—especially for those with incomes too high to qualify for Medicaid and too low to be able to afford a lot of care on their own. Some of this should be oriented toward non-traditional services, such as transportation support and training for family caregivers (Donelan et al., 2002; Levine et al., 2010; Schier, Ginsburg, Howell, Bolland, & Golden, 2013).

Another key resource need is for intellectual and emotional support that goes beyond the basic notion of a home care aide who is helping with eating, bathing, and dressing, for example. And finally, the length of time that help is needed is much longer than the resources currently available from Medicare. The only thing that is certain is the need for more resources—both from the public sector and from the informal services provided by family and others. In this tough political environment, I am not optimistic about the prospects for public resources in the near term.

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