

CHAPTER 2

LONG-TERM CARE AND LONG-TERM FAMILY CAREGIVERS: OUTDATED ASSUMPTIONS, FUTURE OPPORTUNITIES

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I am having an identity crisis. When my husband Howard suffered a severe traumatic brain injury in 1990, I was his wife. Not a “good” wife, as I was repeatedly told by nurses and social workers at a rehab facility, but a “bad” wife who was unable to control her quadriplegic brain-damaged husband’s rages, refused to take him home without some assurance of help, and failed to take professionals’ advice to quit her job and spend down to make him eligible for Medicaid.

Five years later, after I had created a fragile, private-pay arrangement at home, I finally realized that I was not a bad wife but a beleaguered one dealing with a dysfunctional system. Without any orientation or guidance, I had been transported, like Alice through the looking glass, into the bewildering world of “custodial” or long-term care. In my discussions with various agents of bureaucracies, I gained a new appreciation for Humpty Dumpty’s maxim, “When I use a word, it means just what I choose it to mean—neither more nor less” (Carroll 1872). For example, a “two-person” transfer in rehab meant two nurses or aides had to be present to move my husband from bed to wheelchair. At home, however, only one person was needed for a two-person transfer. That would be me.

This chapter differs from the others in this volume in its blend of my personal experience as a caregiver and my professional experience as a health policy and medical ethics researcher, editor, and writer. From my perspective, this book’s question: “Universal Coverage of LTC in the U.S.: Can We Get There from Here?” has been answered. We already have near-universal long-term care coverage: it is family care, with Medicaid as a “safety net” with gaping holes. This chapter looks at a slightly different question: How can public policy best support long-term family care? Based on the realities of an aging population, financial shortfalls, and workforce shortages, all described in detail in other chapters, I assume that family care will continue to be at the heart of any form of universal or near-universal long-term care coverage. This dependence on families is rarely explicit in policy proposals for home- and community-based care, although it is surely implicit. More important, in my view, removing family care from the long-term care equation would not be good for older people, their families, or society. Families want to and will continue to provide care; but they should not be expected to do it alone.

“Health statistics represent people with the tears wiped off.” This statement, attributed to the British epidemiologist Sir Austin Bradford Hill, is particularly apt when applied to family caregivers. Sometimes the tears hidden in caregiver statistics are tears of grief, loss, and isolation; sometimes, though, they are tears of anger and frustration brought on by the indifference, lack of information, and even hostility they experience in their encounters with the health care and long-term care systems.

Family caregivers today are ill-served by entrenched health and long-term care systems developed in the 1970s and 1980s. The language, policies, and programs of these systems do not reflect the realities today’s caregivers face. There are new opportunities for change, but they require rethinking some basic policy assumptions and professional practices. This is culture change of a major magnitude.

This chapter first describes the family caregiving population today, which is large and diverse, and suggests some research limitations that have impeded a full understanding of the experience. Second, it looks at family caregiving through a policy lens. Efforts to control health care costs, as well as changes in medical practice and technology, have resulted in more responsibility and more complex tasks being offloaded to untrained and unprepared family caregivers. Yet family caregivers do not generally see themselves as part of the workforce. Finally, the current emphasis on reducing hospital readmissions has created an opportunity for bringing long-term and health care together through a belated recognition that safe and effective transitions in care settings depend in large part on prepared and supported family caregivers.

From Care to Supports and Services

In 1996, frustrated with my inability to navigate the shoals of long-term care in the “community” (an ill-defined concept in its own right), and perceiving an opportunity for research and advocacy, I changed the focus of my professional work from AIDS policy and ethics to the challenges facing families caring for aging or disabled relatives. I soon learned from the literature that I was not a wife but an “informal” or “spousal” caregiver, a research and policy designation that distinguished unpaid caregivers from paid professionals and aides. “Spousal” typically meant an older, unemployed or never-employed, always-on-call woman. Since “informal” clearly did not describe the demanding challenges and responsibilities I had taken on in addition to a full-time job, I opted for the alternate designation of “family caregiver.”

Now I find that after all those years (my husband passed away in 2007), I should have had a different title. I was not providing long-term care, as I thought, but long-term services and supports, now the preferred, albeit not universally accepted, terminology. Should I have been calling myself a “family long-term service and support provider”?

I understand the reasons behind this change as a way to establish the primacy of independence and self-management for (mostly) younger, competent disabled people who don't want "care" but do want control and prefer to keep their families out of their daily routines.

Many older adults also want and should have the power to direct the most intimate aspects of their lives. But the most vulnerable and most in need of assistance—my late husband, say, or an 85-year-old woman with dementia and multiple chronic conditions—need care, not control. Certainly services and supports are part of care but substituting this impersonal and bureaucratic language diminishes this primary human need.

In the widely accepted view that long-term care is personal care, medical care is seen as episodic, related to acute, treatable illness or trauma, and provided and controlled by doctors, nurses, other medical professionals, and insurance payers. Chronic medical care is part of long-term care except when it isn't. Medicare's definition is illustrative. "Long-term care is a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom (Medicare.gov 2010). Yet, this separation of medical from other kinds of care is not what most ordinary people think of as long-term care, especially for someone with multiple chronic conditions that require multiple daily medications, frequent doctor visits and tests, and other medical interventions. Humpty Dumpty strikes again.

Family Caregivers: The Big Picture

In one way or another, every article on long-term care has some statement like these: "Family members are far and away the principal providers of assistance to the long-term care population living in households" (Kaye, Harrington, and LaPlante 2010) or..."reliance on informal care remains very much the backbone of the U.S. system of long-term care for older Americans with chronic functional disabilities" (Doty 2010).

Yet the perception that Americans have abandoned their elderly relatives en masse remains entrenched in the public's mind and to some extent in uninformed policy makers' considerations as well. In a conversation with Ramraj Gautam after the meeting on which this book is based, I learned that he routinely asks his introductory gerontology class in the school of nursing at the University of Massachusetts-Lowell to estimate how many older Americans live in nursing homes. The initial estimates range as high as 80 percent. When he asks them to estimate the lowest percentage they

feel is reasonable, it is still around 25 percent. Comments on blogs about aging and family caregiving routinely decry families' supposed rush to put Grandma in a nursing home and forget about her. For example, one anonymous blogger wrote (October 8, 2008) to "The New Old Age," a *New York Times* blog, "North American Indians did not discard their aging family members like disposable products or no longer wanted pets." Another wrote: "We live in an age of barbarism towards the old."

Yet a relatively small percentage of older adults actually reside in nursing homes, and some of them provide high-quality care. According to 2009 estimates of the U.S. Census Bureau, 12.9 percent of the population, or 36.9 million people, are 65 years or older. That number is predicted to increase to 86.7 million, or 21 percent, by 2050. Currently, 1.5 million to 1.8 million people, or about 4 percent, live in nursing homes at any given time. The likelihood of spending some time in a nursing home increases with age.

Nursing home residents are typically the oldest old and also the frailest old. There has been an increase in the residents aged 31 to 64, from 10 percent in 2000 to 14.2 percent in 2010, largely due to cuts in state Medicaid payments for home attendants and mental illness in this population (Shapiro 2010). Two thirds are female with a median age of 82. Notably, 92.8 percent have mobility impairments, 75.8 percent cognitive impairments, and 37.2 percent sensory impairments (Kaye, Harrington, and LaPlante 2010). Long-stay nursing home occupancy has actually been declining, as states have tried to close beds and increase community services and as nursing home operators have marketed their short-term rehab services for financial reasons. A portion of the healthiest and wealthiest elderly population, estimated at 900,000, reside in assisted living facilities (National Center for Assisted Living 2012).

Even when their family members live in nursing home, many family caregivers are still actively involved. Although they do not provide as much hands-on care, they have important roles as advocates and care monitors. Because there are so many variables, measuring the frequency of contact between nursing home residents and their family and friends presents a methodological challenge (Port et al. 2003). One five-year longitudinal study found that the majority of caregivers maintained the frequency and length of their visits for extended periods of time (Yamamoto-Mitani, Aneshensel, and Levy-Storms 2002). Another study found that spouses visited more frequently, and that those who perceived that their social network respected and supported the choice to institutionalize their family member were more likely to visit (Gaugler, Zarit, and Pearlin 2003). Yamamoto-Mitani et al. (2002) concluded that "To a large extent, family visits to nursing home residents with dementia become established in the period immediately after relocation, which means that efforts to

enhance continued family involvement should commence at the time of admission” (p. S234). This is consistent with a report on family involvement which concluded that “[f]amily members are a crucial part of a team approach to resident and patient care... The intensely busy schedules of staff in long-term and post-acute facilities make it even more important to work collaboratively with family members” (Gerzon 2010: 41).

While public policy focuses on nursing homes, most older people live in their own homes or with family. They have not been abandoned. Those who need assistance receive all or most of the help they get from family members and may never need nursing home placement. Despite the oft-proclaimed wish to die at home, most people still die in hospitals.

Prevalence and characteristics of family caregivers

How many family caregivers are there? The estimates range widely, depending on the definition of caregiving, the population surveyed, and the methodology, for example, whether caregivers were identified by people with disabilities or by people who identified themselves as caregivers (Giovannetti and Wolff 2010). The most recent estimate—62.5 million—comes from the 2009 National Alliance on Caregiving/AARP telephone survey, which found that about 28.5 percent of the respondents reported being caregivers, similar to its 2004 survey results (National Alliance for Caregiving 2009). This total includes caregivers of people of all ages, including children with disabilities; about 43.5 million caregivers take care of someone over the age of 50. One third of these caregivers take care of two or more people. An earlier survey of children aged 8-18 estimated that 1.4 million minors were engaged in caregiving, often doing the same things adults do (Hunt, Levine, and Naiditch 2005). Other survey methods obtain different, generally lower results. Although somewhat outdated in terms of survey results, a side-by-side comparison of methodologies prepared by the Family Caregiver Alliance is a useful reference (caregiver.org 2001). This unpaid care is currently valued at \$375 billion a year (Houser and Gibson 2008), an increase from the \$196 billion estimated in 1999 in the first use of this methodology (Arno, Levine, and Memmott 1999).

The surveys agree that the majority (two-thirds) of family caregivers are women in their middle years taking care of older women. In the 2009 National Alliance on Caregiving survey, the average age of caregivers taking care of people of all ages was 48, and the average age of the care recipient was 61. In the same survey analysis of caregivers of people over the age of 50, the average age of the caregiver was 50, and the average care recipient was 77. But the composite making up the picture of an average caregiver should not conceal the picture’s diverse elements. Caregivers are

men as well as women, spouses and partners, adult children, minor children, friends and neighbors, people of all religious, economic, and ethnic backgrounds.

On average, family caregivers spend about 20 hours a week assisting their family member. Like the composite description, this average is made up of caregivers who spend eight to ten hours a week as well as those who have to be available all day, every day (and what is even harder, all night, every night). The big picture also includes caregivers whose responsibilities are fairly simple, such as shopping and making meals and just checking in, to complex medication management and operation of medical equipment like feeding tubes, ventilators, and IV infusions, or keeping a person with advanced dementia safe and comfortable.

Impact of caregiving on mental, physical, and financial health

Substantial research has documented that the stresses of caregiving take a toll emotionally, physically, and financially. Not all caregivers experience problems but the longer one is a caregiver, the more likely it is that there will be serious consequences. Some of the stress results from seeing the family member decline as well as the specific stresses of caregiving over time. I know of no time parameters for “long-term.” I meet caregivers who are desperate after a few months of caregiving and others who are doing well after five or more years. Most caregivers underestimate the length of time their family member will need care, and weeks turn into months and months into years. The average length of stay in a nursing home is about 2.4 years, suggesting that many years of care have likely preceded this stage. Many family caregivers agonize over the decision to place a family member in a nursing home and make it only when the situation become untenable at home or when the relative is hospitalized and is discharged to a nursing home.

Here are some representative statistics. Between 40 and 70 percent of family caregivers have clinically significant symptoms of depression (Zarit 2006). These symptoms increase as the care recipients’ condition declines. Placing the family member in a nursing home does not necessarily lessen anxiety and depression because of guilt, loss of control, and worries about the quality of care. Caregivers who provide 36 or more hours a week of care have the highest level of depression.

Many caregivers suffer from high levels of stress. The Evercare study of “Caregivers in Decline” found that “when caregivers talk about their worsened health, stress seems to be the most pervasive health problem in their lives...Caregivers believe that the stress takes physical form as some of the other health problems they report, including increased blood pressure, heart attack scares, arthritis flare-ups, acid reflux, headaches, and other conditions”(National Alliance for Caregiving 2006: 5). One of

the most common topics at caregiver workshops is “stress reduction,” which usually involves breathing exercises and meditation techniques. Caregivers feel angry, drained, guilty, helpless, and isolated. Most studies focus on stress related to the demands of caregiving, balancing different roles and responsibilities, or the dynamics of the relationship with the care recipient or other family members.

Unfortunately, few studies ask whether the difficulty of dealing with health care or social service professionals or the bureaucracies in which they work is a significant source of stress. One of the few studies to ask about this aspect of caregiving is the 2008 study of employed current and former caregivers conducted by the Work and Family Institute (Aumann et al. 2010). Over a third (36 percent) of former caregivers reported that professionals had made medical errors in the care of their relatives. In some cases the mistakes were so serious that the caregivers believed that they contributed to their relative’s death. There was no independent verification of these beliefs; what is important is the lack of trust in the health care system that they reveal. When asked about their top wishes for the way in which doctors, nurses, and other in the health care system could support family caregivers, they reported: “more frequent and better quality two-way communication; less overworked, more compassionate staff at medical and nursing facilities with the skills to listen and learn from the caregivers and the elders; and a more user-friendly easier-to-navigate and less costly health care system” (Aumann et al. 2010: 3).

Caregivers’ physical health suffers as well as their mental health. They are generally in worse health than their non-caregiving peers. They are at increased risk of heart disease, stroke, and dementia. Immune system deficiencies have been well documented; if a caregiver actually finds time to get a flu shot (as frequently advised), its protection is not as strong because of the lowered immune response. Joint and muscle problems are common, often exacerbated by the lifting, moving, and pushing needed to take care of someone who has mobility problems or is in a wheelchair. Sleep deprivation is very common. Increased mortality is the ultimate caregiver sacrifice. In one study older caregivers who reported strain were 63 percent more likely to die than their noncaregiving peers (Schulz and Beach 1999).

Most caregivers do not like to dwell on the financial sacrifices they make or even to tally them. Only 15 percent of the respondents to the 2009 National Alliance for Caregiving reported serious financial hardship, with the highest percentage (22 percent) among the lowest income group. Perhaps it seems wrong to worry about money when your family member needs your help. But the financial impact of caregiving does take a toll. Out-of-pocket expenses can be a constant drain, especially travel for long-distance caregivers. Expenditures for all the things not covered by

Medicare and commercial insurance—copays, disposable items, extra help, assistive devices, home modifications, or a customized wheelchair—add up. In an era of widespread unemployment, when two incomes are needed to meet basic family needs, this financial drain can be severe.

If caregivers do not think a lot about the short-term drain on their finances, they are largely oblivious to the long-term impact on their retirement and their own long-term care needs. People in their 40s and 50s often cannot or will not think about saving for their own future needs when their parents' and children's immediate needs are more pressing (see Chapter 10 on long-term care insurance).

Half of all caregivers are employed full- or part-time. In the 2009 National Alliance on Caregiving/AARP study, 70 percent of workers reported that caregiving had an impact on employment. Two thirds went to their jobs late, left early, or took time off. Twenty percent took a leave of absence. Some caregivers turn down promotions or opportunities for enhancing their skills because it will interfere with caregiving. Some large employers have established flexible policies for family caregivers, but most have not. Some businesses are totally supportive or generally tolerant. Others do not make any adjustments for caregivers. For their part caregiving employees are reluctant to acknowledge their dual responsibilities in their workplaces lest this be seen as shirking their workload and perhaps jeopardizing their job.

The Families and Work Institute's study of employed caregivers adds depth to this picture (Aumann et al. 2010). The study found that 42 percent of individuals in the workforce—an estimated 56 million--had provided elder care over the past five years. Unlike other surveys, this study found that employed women and men provide care in roughly equal numbers. However, women are more likely (44 percent) than men (38 percent) to provide care on a regular basis rather than intermittently. Despite their caregiving responsibilities, family caregivers work at their jobs as many hours on average (45 hours) as those who are not caregivers. Family caregivers were asked for their top wishes for the way in which workplaces could better support them. Their answers were: "greater flexibility, more options for managing time; time off for elder care, especially time off without having to use up vacation time; and more understanding of their situation from management" (Aumann et al. 2010: 3).

Despite this litany of problems, it is important to remember that not all caregivers are equally vulnerable. Older caregivers are particularly at risk, as are poor caregivers and those with chronic health problems. Caregivers with language or health literacy difficulties have a hard time navigating the various systems. Caregivers taking care of more than one person are obviously doubly challenged. But all caregivers may be at risk in different ways, such as financially and emotionally.

For many caregivers, there are rewards as well as stresses and strains. This is an area that is less studied than the problems caregivers face, and a fertile ground for research. Is it entirely a matter of financial resources and family support, prior relationships with the older person, and perhaps personal temperament? Or are there ways to encourage the rewards while lessening the strains? Many caregivers learn new skills. They may enjoy the extended time spent with their family member, and gain a new perspective on that person's life. Some feel satisfaction, a sense of a duty fulfilled, even if they do not have a particularly loving relationship with their family member. Prayer is the most commonly cited coping technique, and many caregivers report spiritual growth.

Interestingly, one of the findings of the Families and Work Institute study was that only 14 percent of current caregivers reported that caregiving has improved their relationship with the person they care for. That percentage rose dramatically—to 60 percent—when caregivers whose relative had died were interviewed. The authors suggest that “Quite possibly, caregivers do not have enough time or mental resources to reflect on the caregiving experience and the relationship with the care recipient until after [it] is over” (Aumann et al. 2010, underline in original). It is hard to search for meaning and transcendence in an earthquake when the walls are shaking around you. Bereavement services should allow for individuals to search for their own meaning, a healing process that cannot be rushed.

Research Gaps and the Limitations of ADLs and IADLs

This is only the barest summary of what is known about family caregivers. Despite the numerous studies conducted in the past forty years, there are serious gaps in knowledge. More studies have looked at certain groups, for example, caregivers of people with Alzheimer's disease or other dementias, more than others, such as people with disabling arthritis or diabetes. In contrast, children and young adults who do the same tasks as older caregivers are hardly studied at all, at least in the U.S., and are rarely even considered to be caregivers. There is a considerable body of research from the UK, where all carers (as they are called), including children, are counted in the census (Aldridge and Becker 2003; Dearden and Becker 2004). The tyranny of the average—the middle-aged woman caring for her elderly mother—dominates most media portrayals and other discussions as well.

Another problem is the nearly universal reliance on the ADL-IADL scheme to describe what caregivers do. These measures date from the 1960s; the original ADLs were developed to measure how well older adults were recovering from hip fractures and could go home. IADLs were added to take account of the individual's ability to manage at home. As Susan Reinhard points out in her analysis of these measures,

“When family caregiver research began in earnest in the 1980s, researchers applied the ADL and IADL scales to caregivers, on the assumption that what caregivers provided was the mirror image of the functional limitations of the care recipient. While this approach has intuitive appeal, it fails to consider many aspects of caregiving” (Reinhard 2004: 37). Furthermore, she asserts that there is so much measurement error in ADLs even for their intended purpose that using them as a proxy measure for caregiving was flawed from the outset. Nevertheless, the use of ADL-IADL measures in public policy began in 1982, with the first informal caregiver supplement to the National Long-Term Care Survey of Medicare Beneficiaries, and has continued ever since. This inadequate structure is the basis for policy decisions and eligibility for publicly funded services and many long-term care insurance benefits.

Consistent with the definition of long-term care as personal care, neither ADLs nor IADLs pay much attention to the medical tasks (medication management, wound care, symptom monitoring, communication with medical professionals, and the like) that typically are family caregiver responsibilities. The only national survey that specifically identified medical tasks found that 54 percent of the respondents reported that the person they cared for was hospitalized overnight in the year prior to the interview, and 74 percent said that this person had a serious or chronic illness. The survey included several measures that are not typically asked: wound care, pumps and machines at the bedside, and medication administration. Over 40 percent performed at least one of these tasks, and 26 percent helped to give five or more medications. Most received little or no training from professionals (Donelan et al. 2002).

Among its several flaws, the ADL-IADL scheme fails to take account of the variations in degree of difficulty. Help in bathing can mean anything from making sure that the water isn't too hot or cold and that the towels are easily reached to managing to get a demented patient into the shower when she does not remember what a shower is and is sure the caregiver intends to drown her. Nor do these measures even begin to acknowledge the skills required to manage the insurance and financial or legal needs of the care recipient.

Steven Albert says that the ADL-IADL measures “will always be an imperfect guide” to describe caregiving because they are “both too gross and too narrow.” They are too gross, he says, because they “do not specify fully what it means to help with ADLs and IADLs” and too narrow in that they “do not cover the full range of tasks caregivers typically do” (Albert 2004: 99). He goes on to propose a new formulation that would incorporate four features of the context in which caregiving takes place:

- Timing—whether care is required rarely, frequently but in predictable ways, or frequently in unpredictable, unexpected ways.
- Caregiving proximity—whether it is enough that the caregiver is in the house while someone eats a meal or bathes or must the caregiver be in the same room standing by or providing hands-on help.
- Effort—the level of effort required, from coaxing to complex guidance and control.
- Participation of the care receiver—whether it is active, passive, or resistant.

A new generation of research is needed to develop new measures, new approaches, and new ways to describe the varied and complex roles caregivers play.

We also need more information on how the care receiver perceives the care provided by family members, particularly personal care and medical tasks. Well-meaning professionals and friends say, “What’s the big deal? Your mother changed your diapers. You can do the same for her.” But what does Mother think about this? Does she accept this as a quid pro quo for services performed in a totally different situation fifty years ago or does she feel humiliated and angry? Do care recipients trust the family caregiver to monitor the machinery and give the right pills when their experience has been that this person is irresponsible in other aspects of his or her life? Does accepting care inevitably mean loss of independence? The respondents in the Work and Family Institute survey named as their top challenge in their relationship with their family member “striking a balance between dependence and independence, getting the elderly relative to accept help and embrace a positive or cooperative attitude” (Aumann et al. 2010). Culture plays a large role in this role shift, and attitudes may vary considerably about what is proper behavior between a father and daughter, for example.

Through the Looking Glass: LTC Policies and Family Caregivers

Long-term care and health care systems have been separated by their cultures, disciplines, funding, and power. Anything that looks like a “medical model” is often distrusted by social service staff; anything that looks like “social care” is similarly handed off by medical staff. The family caregiver is left to negotiate the boundaries. Furthermore, advocacy for family caregivers has largely been part of the less-powerful, less well-funded aging and social service network. Medical champions of family caregivers are rare, although their numbers are increasing; often physicians and nurses see the family as “intrusive,” “dysfunctional,” and a hindrance to doing their jobs (Levine and Zuckerman 1999).

Policy makers have been ambivalent about family caregivers, fearing that public funding will replace free family care, although multiple studies have shown that it does not. They also worry that without some support family caregivers will not be able to sustain this role and will place their relative in a nursing home at even greater public expense. They have generally resolved their ambivalence by extolling family caregivers in public, supporting some measures designed primarily to control costs, and failing to fund adequately significant initiatives that do not promise an economic payoff.

The artificial separation of long-term care from medical care has long historical roots but was given its current incarnation in 1965 with the advent of Medicare, which was designed to pay for the acute care needs of individuals over 65. Medicaid was added at the last minute to replace the state-run Old Age Assistance models that in turn had replaced poorhouses and indoor relief. As David Barton Smith and Zhanlian Feng put it, “Long-term care [in the period 1910-1930] was, in essence, the last holdover of the Elizabethan poor-law approach.” They observe that Medicaid emerged as the default payer for long-term care, partly because of its late addition to the Medicare legislation and “a lack of attention to long-term care in the overall reform package, and the historical tradition of states’ assuming the responsibility of welfare programs. The ultimate effect was to relegate long-term care to a welfare system largely segregated from the mainstream of medical services” (Smith and Feng 2010) and, one might add, still bearing a taint of its historical stigma.

Medicare is a form of social insurance, a program to which employees contribute in anticipation of benefits when they reach 65; Medicaid is a social welfare, means-tested system. We have been living with both the benefits and unanticipated consequences of these distinctions ever since. Because Medicare does not pay for long-term care, long-term care policies and programs are essentially shaped by Medicaid, or for those dually eligible, by Medicaid and Medicare.

Family caregiver support services generally follow the services to which their family member is eligible. There are a few federal programs with eligibility not based on Medicaid, but these are inadequately funded. The National Family Caregiver Support Program (NFCSP) was established in 2000 under Title III E of the Older Americans Act. It is administered by the U.S. Office of Aging and provides grants to states, which disburse funds to local Area Agencies on Aging. The NFCSP provides information and referral, counseling, respite, and other services. Its budget in fiscal year 2008 was \$153.4 million, including set-asides for Native Americans and grandparents caring for grandchildren (Administration on Aging 2010). The Lifespan Respite Program (PL 109-442) was enacted in 2006 but funded only in 2009, with an

initial \$2.5 million to be awarded to states through a competitive grants process (Family Caregiver Alliance 2010).

Using Medicaid and their own resources, states have developed their own programs in the effort to “rebalance” services from institution to community. A review of home- and community-based services across the states found that there are five major revenue streams: Medicaid waivers, programs and grants funded by the Centers for Medicare and Medicaid Services, state-funded programs, Medicaid State Plans, and Title III of the Older Americans Act (Rose et al. 2010). While the many variations across states can be seen as tailoring programs to local needs, Terence Ng and colleagues assert that:

“Home and community-based services programs often have different administrative structures, financial eligibility criteria, screening and assessment procedures, provider recruitment and management, reimbursement structures, and quality oversight procedures. The many state home- and community-based services programs are administratively costly and confusing to consumers [including family caregivers] and providers” (Ng, Harrington, and Kitchener 2010: 26).

A listing of programs does not tell much about whether the services are actually available and their quality. Moreover, these programs have waiting lists and are particularly vulnerable to state budget cuts (Leland 2010).

Many services available to family caregivers are provided by nonprofit organizations, dedicated to specific diseases or communities. Finding appropriate services, particularly for a long-term family caregiver whose family member is not eligible for Medicaid, remains a challenging and frequently unsuccessful task.

Caregivers as Part of the Workforce

In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine called for a new perspective on family caregivers: “The definition of the health care workforce must be expanded to include everyone involved in a patient’s care: health care professionals, direct-care workers, informal caregivers, and patients themselves. All of these individuals must have the essential data, knowledge, and tools to provide high-quality care (Institute of Medicine 2008: 1). However, health care professionals do not see family caregivers as part of their workforce, nor do family caregivers see themselves in that role. Often they do not even see themselves as caregivers, but as spouses, daughters, sons, or friends. Organizing these disparate individuals with little in common except their caregiving role is hard enough; gaining enough political power to counter entrenched economic and professional interests is even harder. Only when there is a compelling

case—such as the caregivers of “Wounded Warriors” (service personnel injured in Iraq and Afghanistan)—does caregiver advocacy rise above political and economic barriers (see <http://www.woundedwarriorproject.org/>).

One policy initiative does see family caregivers as part of the workforce and even pays them. This is consumer- or participant-directed home care. The most well-known program, Cash and Counseling, has been introduced in twelve states beyond the original pilot projects in Florida, Arkansas, and New Jersey. These programs are intended to give people receiving Medicaid personal care services more control over their care by allowing them to use a monthly budget to hire and pay their own workers, including family members and friends (Simon-Rusinowitz et al. 2010b). Another impetus has been the difficulty of finding direct-care workers, particularly in rural areas.

A panel of experts in long-term care recently recommended an expansion of these programs as a way to recruit and retain family caregivers. The panel noted that this approach benefits family caregivers as well as consumers because it “also provides family caregivers with much needed financial compensation, especially when their earnings in the paid workforce are diminished because of caregiving responsibilities or there are financial expenditures related to the care recipient’s needs” (Noelker et al. 2010: 22).

Similarly, a review of Cash and Counseling programs suggests that family caregivers “could be targeted for recruitment as professional caregivers and that family caregiving has the potential to increase significantly the direct care workforce” (Simon-Rusinowitz et al. 2010a). Some former family caregivers do go on to paid jobs as home health aides. However, it is doubtful that former family caregivers make up a large pool of potential direct care workers. As some members of the expert panel on long-term care pointed out, “former caregivers are often burned out and, if they are looking for employment, are likely to be looking for more lucrative opportunities” (Noelker et al. 2010). At a meeting a few years ago I heard a well-known female physician offer her solution to the need for caregiving workers: “Just pay all these working women to stay home!” No one dared to ask her whether she included herself in that group.

Respondents to the 2009 National Alliance for Caregiving/AARP survey identified tax credits and vouchers by which their relative would pay them a minimum wage for some of the hours of care they provide (the Cash and Counseling model) as top policy preferences. None of the survey choices was explained so it is not clear that the respondents understood the difference between tax refunds and tax credits, which would be subject to specific requirements. Nor was it clear that for a family caregiver

to be paid, the relative would have to be on Medicaid and that this arrangement would be in lieu of agency help, not a supplement to it. Nor would the payment come with benefits like health insurance. Clearly, money was important to these respondents, even though only 15 percent reported financial hardship. The third most desired option was respite services; other choices were: assessment of their capabilities and needs with referrals to services, partially paid leaves of absence, and outside transportation services.

DRGs and Cost Containment

Since their inception, Medicare and Medicaid have gone through cycles of expansion and retrenchment. Prospective payment in the form of Diagnosis-Related Groups (DRGs), introduced in hospitals in 1983, was the first major cost-containment measure. Instead of paying hospitals “reasonable costs” for treating Medicare and Medicaid patients, which gave hospitals and physicians control over spending, prospective payment sets predetermined payment rates based on diagnosis. In the DRG system a patient who can be discharged home before the standard number of days for that diagnosis is an economic benefit to the hospital, just as the longer-stay patient results in a financial burden. Whether patients have been discharged “sicker,” there is no doubt that they have been discharged “quicker.”

Even patients with complex illnesses requiring technological support like ventilators, IV infusions, and total parenteral nutrition can be sent home with equipment and a modicum of formal home care support. As hospital length of stay decreased under DRGs, home care agencies grew rapidly until the Balanced Budget Act of 1997 reduced their ranks and Congress introduced prospective payment systems for home care and nursing homes. The medical technology industry grew as well, meeting the demand for high-tech equipment for home use. The pharmaceutical industry flooded the market and television screens with expensive medications for chronic conditions, many with benefits but also risks. Families provided the bulk of care, as they always had, but now it was not just to the frail older person who needed a little help managing around the house, but a patient with hospital-level care needs (Arras 1995). This trend is not limited to the U.S.; Australian authors have called it the “invisible contract” with family members (Dow and MacDonald 2007).

Starting with DRGs but growing in fervor in the past decade, cost-containment has been the mantra of policy makers, providers, and the public. Yet the perfect storm that took medical care out of hospitals and professionals and put it into the home and the hands of untrained family caregivers is still raging. With rising insurance deductibles and copays, home care and rehab service limitations, and other cost-shifting practices,

families are left not only to provide more demanding care but also to pay for a greater percentage of it.

Transitions in Care: The New Frontier for Family Caregivers

The high-tech/low-tech, social/medical distinctions that have governed long-term care for the past fifty years are outdated. The reality that medical and long-term care is part of a spectrum of individual needs is a truism that has yet to be incorporated into policy and practice. As Robyn Stone points out, “The boundaries among primary, acute, and long-term have been blurred. Instead of concentrating on acute care in hospitals as before, our health system is increasingly devoted to chronic care by various providers in various settings” (Stone 2000: 2). The frequent moves from skilled nursing facilities to hospitals and back again has been called a “revolving door” by Vincent Mor and colleagues. They found that a quarter of Medicare beneficiaries discharged from a hospital to a SNF was readmitted to the hospital within 30 days at an annual cost of \$4 billion (Mor et al. 2010).

Some of the reasons behind this trend toward more diversity in postacute care are financial. Between 1999 and 2007 Medicare postacute spending grew more than the number of new users. Nursing homes have expanded their short-term rehabilitation programs, preferring the higher Medicare reimbursement for postacute services than Medicaid’s reimbursement for long-term care. Ng and colleagues assert that “Although Medicare postacute and Medicaid long-term care services are intricately related, they are poorly coordinated and have competing incentives. Medicare focuses on reducing hospital and postacute use and costs, resulting in shifts to the Medicaid long-term care program. That program, in turn, has little incentive to reduce Medicare hospital and emergency room use (Ng et. al. 2010: 27-28). Caught in the middle is the family caregiver, whose family member is moved from one setting to another because financial incentives may compete with good patient care and patient and family preferences.

The moves to and from these different settings—each with different staff, rules, culture, and expectations of patient and family caregiver—is the new normal in health care. Transitions in care settings can occur within the hospital from ER to ICU to regular floor, from hospital to home or to short-term rehabilitation program in a skilled nursing facility or inpatient rehab hospital, from rehab to home or to a long-stay unit in the same or different nursing home, and from the opening to closing a home care case. Often these transitions are abrupt and inadequately planned. As Mor and colleagues point out, “Especially in an elderly population, cycling into and out of hospitals can be emotionally upsetting and can increase the likelihood of medical errors related to care coordination” (Mor et al. 2010: 57). Coleman and colleagues

studied the patterns of post-hospital care transitions and found 46 distinct types of care patterns experienced by Medicare patients over a 30-day period (Coleman et al. 2004). Between 13.4 and 25 percent of these transitions were described as “complicated,” i.e., the patient did not go directly home but moved once, twice, or three times between settings (8.1 percent died with the study period). A systematic review of studies of the determinants of preventable hospital readmissions found significant variation in index conditions, readmitting conditions, timeframe, and terminology (Vest et al. 2010).

Given this complexity, there is no typical pattern of transitions. But the following hypothetical example, based on Coleman’s work and the Institute for Healthcare Improvement’s list of typical failures in transitions (Institute for Healthcare Improvement 2009) brings this profusion of factors to a concrete level. This is neither a worst-case nor a best-case scenario; it is simply a common-enough scenario (for a geriatrician’s view of a multiple-transition case, see Gillick 2010).

Mrs. Jones, an 81-year-old widow who lives alone and manages fairly independently, although recently she has begun to have memory lapses. Her daughter, Louise, lives nearby and helps her mother manage her medications for her heart condition and hypertension and pays her bills. One day on her way to the store Mrs. Jones falls and breaks her hip. She also hits her head on the sidewalk and is confused and disoriented. A passerby calls 911, and an ambulance takes her to the nearest Emergency Department (not the hospital where her doctor has admitting privileges). She is admitted to the hospital and has surgery to repair her hip. She spends several days in the ICU where she develops delirium and is given a psychotropic drug before being moved to the regular floor. All this time Louise has been standing by, getting bits of information from different doctors but without a clear understanding of her mother’s condition or what is going to happen next. Mrs. Jones is recovering reasonably well from surgery but her confusion and disorientation persist.

After only a day on the hospital floor, Louise is told on Friday morning that her mother is being transferred that afternoon to a nursing home for rehab. Louise protests that she wasn’t consulted on this move and does not want her mother to go to a nursing home. She is told (incorrectly) that if she does not accept this transfer, she will have to pay for the additional hospital care. No one explains her right to appeal. Mrs. Jones is transported again by ambulance to a nursing home. By then it is late evening and the nursing home is short-staffed and not ready to receive a new patient. No medications have been sent with Mrs. Jones, although she needs regular doses of pain and heart medications. The medication list, when it does arrive, does not contain all the changes made in the hospital.

After a weekend when nothing happens, Mrs. Jones begins therapy on Monday. She complains of dizziness and nausea, which turn out to be related to the psychotropic drug. After a week she develops an infection near the surgical site and is sent back to the ED and then readmitted to the hospital. Louise finds out about the transfer only when she goes to visit her mother at the nursing home. After the infection is treated with IV antibiotics (which might have been done in the nursing home), she is discharged, this time to a different nursing home because there is no bed available at the first one, and Louise declined to pay for a bed hold. After two weeks of therapy, Mrs. Jones has reached a plateau and is not improving. Louise is told, again incorrectly “Medicare won’t pay” (Levine 2010). Her mother is sent home with a referral for home care services, which Medicare will cover in part. Home care services consist of a weekly nurse visit and a physical therapist twice a week. A home health aide comes three days a week for four hours a day. Louise takes time off from her job because her mother cannot be left alone.

In three weeks, the home care services end because Mrs. Jones no longer needs a skilled service. There are two possible future scenarios: Mrs. Jones has recovered well enough to resume her life, more or less as before, with perhaps a little more help from Louise in terms of shopping and transportation. Or, the whole cycle may be repeated, with more falls and hospitalizations, leading to further cognitive and physical decline. After one or more downward cycles, Louise will realize that her mother cannot live independently anymore, nor can she devote her full-time efforts to her care. So Mrs. Jones will enter the long-term care system through admission to a nursing home in worse shape than she was before all the interventions designed to help her. Her private resources soon run out, and she becomes eligible for Medicaid. The first fall was the precipitating event, but the subsequent revolving door was a major factor in her decline.

Health care reform has emphasized the importance of reducing avoidable rehospitalizations as a cost-containment measure. Even before the Patient Protection and Affordable Care Act was passed in 2010, with provisions to penalize providers with high readmission rates, efforts were underway to counter this trend. The June 2008 MedPAC Report to Congress recommended that “to encourage providers to collaborate and better coordinate care, the Congress should direct the Secretary to reduce payments to hospitals with relatively high readmission rates for select conditions and also allow shared accountability between physicians and hospitals” (MedPAC 2008: 100).

This directive was given a substantial push by the publication in April 2009 of a study that found that one in five Medicare beneficiaries was readmitted to the hospital

within 30 days at a national cost of \$17 billion a year. Half of the readmitted patients had no contact with a physician after discharge (Jencks, Williams, and Coleman 2009). The Centers for Medicare and Medicaid Services (CMS) are currently writing regulations to determine what counts as an avoidable rehospitalization; states also are establishing their own standards for Medicaid. It is not just rehospitalizations that are the problem; about 10 percent of the nearly 40 million initial hospitalizations in 2008 were potentially preventable. Patients aged 65 and older accounted for 60 percent of these hospitalizations, which were primarily for conditions such as diabetes, dehydration, heart conditions, and infections (Stranges and Stocks 2010).

Improving transitions in care has now moved to the top of health care providers' agendas. Several programs have been developed to achieve this goal; most focus on assessing patients at risk of rehospitalization, providing education about self-management, providing some care coordination after discharge. Only a few explicitly recognize the role of family caregivers (Levine et al. 2010). The United Hospital Fund's 15-month Transitions in Care—Quality Improvement Collaborative (TC-QuIC) is unique in several ways: first, its 28 participant teams from hospitals, nursing homes, and home care agencies work in partnerships across settings, whereas most transition programs focus on hospital to home. Second, recognizing the pivotal role of family caregivers in transitions, it places them at the center of teams' activities. Finally, its goal is to have good transition practices become routine for all staff, not the sole province of a specially hired person. Different aspects of the transition may be managed by different people but they should all be aware of and responsive to the family caregivers' needs in the process. There is no specific goal to reduce rehospitalizations by a certain percentage because so many other elements are involved, although many teams are monitoring this trend.

The teams use elements of the United Hospital Fund's Next Step in Care materials on its website (www.nextstepincare.org), as well as other tools. The methodology is the basic Model for Improvement popularized by the Institute for Healthcare Improvement. TC-QuIC's aims are: to identify and assess the needs of the family caregiver; to integrate the family caregiver into the care plan through processes of medication reconciliation and management and discussion of discharge planning options; to improve the handoff on the day of discharge; and to close the loop with the receiving agency and family caregiver.

Launched in March 2010, TC-QuIC is still a work in progress. Some interesting points have emerged, however, during monthly reports, biweekly collaborative calls and webinars, as well as coaching sessions and onsite visits. First, it is clear that organizations that routinely share patients have never collaborated in a systematic way

to improve transitions. Meeting their counterparts and “walking in their shoes” is something staff see as a major benefit. Second, staff find that talking to family caregivers and assessing their needs is providing important information and insights. One hospital team reported delaying an unsafe discharge because they learned that the elderly caregiver could not manage the care. Third, they are finding that the distinction between health care and long-term care breaks down in practice. One social worker at a rehab facility reported that staff felt a transition had gone smoothly until they learned that the family caregiver had no idea how to get her disabled father into a taxicab when leaving the facility. That essential skill had not been part of the clinical teaching. And a home care nurse found that a husband who had confidently asserted in the hospital that he had no worries about taking care of his wife at home was lost when it came to ordinary household chores like operating a clothes dryer. Simple things, to be sure, but for a caregiver they make the difference between coping and not coping, and for a patient the difference between a successful transition and a return to a facility.

Transitional care initiatives are an important step in closing the gaps created by a fragmented system and bridging the worlds of medical and long-term care. To succeed, however, these initiatives must include family caregivers in designing and implementing change.

Future Directions

Advocates for family caregivers have claimed that health reform will bring many benefits to family caregivers (caregiver.org 2010). Nevertheless, very little help will be available in the immediate future. Many of the programs they cite are pilot projects (Independence at Home Medical Practice and Community Care Transitions Program) or still untried (Accountable Care Organizations). Some adjustments to Medicaid do offer benefits to family caregivers, such as the provision that protects recipients of Medicaid home and community-based services from spousal impoverishment on an equal basis with institutionalized spouses; this provision begins in 2014 and lasts for five years.

From a more skeptical viewpoint, always a prudent place to stand, much depends on how the pilot projects and financial reforms are implemented and whether they involve family caregivers in a meaningful way. To ensure that this occurs, program development and pay-for-performance and bundling schemes, as well as care coordination requirements, should include attention to patient and family caregivers’ needs (Levine, Coleman, and Naylor 2010). The development of a strong cadre of well-trained direct care workers, who could be paid through various insurance schemes, is essential.

More training is needed and not just for family caregivers. The ability to work in a collaborative way with family caregivers should be a core competency for all health care professionals, and it is not now widely taught or mentored. The experience and techniques of skilled physicians, nurses, social workers, and therapists should be used to help their colleagues learn how to communicate, educate, and train family caregivers.

As already noted, we need better research and survey tools that capture the full experience and needs of family caregivers. We also need dissemination of already existing tools like the Centers for Disease Control's optional Caregiver Module of the Behavioral Risk Factor Surveillance System. Important information is now being collected but is rarely available beyond the state offices that conduct the surveys.

Outside the direct health care and social service realm, public policy can do much more to encourage employers to develop caregiver-friendly policies and programs. Creating flexible work arrangements and openness in the workplace about caregiver responsibilities has potential benefits to employers as well as caregivers. Full implementation of the Equal Employment Opportunity Commission's (EEOC) guide to preventing discrimination against employed caregivers would be helpful (U.S. EEOC 2009).

Finally, we need better ways to help caregivers coalesce into a strong and united movement. Family caregivers generally have not been successful advocates for themselves, though they may be vigorous proponents for research for their family member's condition or for better care. Overwhelmed with the tasks of caregiving and often failing to see the policy connections to their situation, they have not been effective lobbyists or organizers. They may tell their powerful stories to legislators, but without a policy initiative they want legislators to sponsor or support. There have been exceptions, of course: advocates for people with Alzheimer's disease or other dementias, returning service men and women, and those who marshaled support for the Lifespan Respite Act. The National Partnership for Women and Families, in its Campaign for Better Care, is attempting to rally supporters for comprehensive change. Its efforts so far have focused on the various programs in the health care reform legislation.

Building a national movement to bring long-term and medical care into a coherent whole and meet the diverse needs of individuals and their family caregivers will take time and a strong political champion. Baroness Jill Pitkeathly, a former social worker and now a lifetime peer in the House of Lords, played this role in the U.K., bringing carers onto the national agenda in a way that has not yet been accomplished in the U.S. despite the tireless efforts of many advocates.

Tentative steps have been taken to break down the silos, but they were built to last and do not give way easily. As anyone who has survived a construction project knows, building a sound structure takes time and incremental, carefully calibrated steps.

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