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The Economic Impact of Elder Care

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People have cared for their elderly relatives throughout human history and across all nations and cultures. Given this, it seems that eldercare should be second nature, something we just do. And yet, in developed countries, in just the past couple of generations, this age-old task has changed. Dramatically.

Once upon a time, people grew up, they grew old, they got sick, and they died. Caring for an elderly relative meant sharing meals, helping out with some chores, and then, for a few weeks, seeing them through sickness and death.

Today, people are not only living longer – into their 90s and beyond – but they are often living these extended years with acute, debilitating illness – illnesses that last not for a few weeks, but years.

Elderly relatives need much more than a little TLC. They need catheters, oxygen tanks, and wheelchairs. They need someone to put a spoon in their mouths, to get them on the toilet, pull on their socks, and remind them what day it is. They need someone to oversee an arsenal of medications and a cadre of medical specialists. And they need someone to make sense of Medicare, Medicaid, Medigap, Plan D, long-term care insurance, senior discounts, reverse mortgages and a seemingly endless stream of medical bills.

But this isn't all that has changed. While the needs to the elderly have grown, the time and availability of caregivers has diminished. In our wildly mobile society, family members often live far apart. Children of aging parents can't just walk down the block or jump in the car to check on mom or bring dad some soup. They often live two hours away – by plane.

Furthermore, women – and the vast majority of caregivers are women – are working, and they are having children later. They are juggling not just work and motherhood, but eldercare too. On a given day they must decide whether to stay at work, go to a teenager's big soccer game, or get mom to her doctor's appointment.

And yet, 80 percent of the care provided to the elderly – this includes help with eating, toileting, dressing, changing bandages, giving medications, etc. – comes from family.

Estimates put the value of this care at nearly \$300 billion each year. I would argue that it is priceless.

Nearly 50 million people in this country care for an elderly relative and these numbers are rapidly climbing. Some 78 million baby boomers are now moving into their 50s and 60s, which means that their parents are between 70 and 95. Eldercare is upon us.

THE IMPACT

There are rewards, of course – intimate moments and loving exchanges, gratitude and reconciliation. People want to care for their loved ones. And yet, the rewards are hard to see when one is in the trenches. The costs to caregivers are phenomenal on many levels.

Time required

First of all, on the most simple level, there is the time involved. Caring for an elderly relative is a part-time job, if not a 24/7 obsession. The average caregiver spends 20 hours a week caring for an elderly person, but many of them live and breathe it. Mom has Alzheimer's, she's moved into the den, and recently she's become hostile and paranoid. She attacks any hired help. Her daughter is the only one who can calm her (although Mom is convinced at times that even her daughter is trying to poison her). The last time she was left alone for a few minutes she tried to warm up some soup and nearly burned the house down.

According to the National Alliance for Caregiving and AARP, 17 percent of family caregivers devote 40 hours a week or more to this task.

Even those caregivers who don't provide hands-on, physical care spend hours upon hours pouring over bills and insurance forms, consulting doctors, calling local service providers, and generally making sure the aide showed up, mom took her medicine, dad ate some lunch, and neither is driving the car.

People sometimes assume that once a parent is in an assisted living facility or nursing home that the family's job is done. But the work doesn't disappear; it simply changes course. Loved ones still need to check in constantly, manage staff, deal with finances, and confer with doctors.

Emotional cost

Beyond the sheer time involved, is the emotional strain, and this is no small matter. Caregivers worry endlessly. They typically feel helpless and confused, as they don't know what to do, how to help, or where to turn. The system is nearly impossible to understand, much less navigate, and what's at stake is dire. They feel guilty that they aren't doing more, resentful that they have to do so much, and anxious that whatever they are doing is wrong. The parent-child relationship, which is already loaded (She's critical of everything I do. He micro-manages my life. My sister was always his favorite), is

turned upside down. They often become isolated, as they no longer have time for friends or any sort of social life. Coupled with all of this, there is grief, because this is, after all, about loss.

Caregivers are typically exhausted, isolated, and overwhelmed. As a result, they often become clinically depressed or physically sick. Volumes of studies show that caregivers have higher rates of depression and morbidity, and generally have a shorter life span.

Strains on family

When you consider the time that is required and the emotions that are involved, it's no small wonder that caregivers have little energy for spouses or children. Marriages are tested, and often dissolve. While men are getting more involved in eldercare, women still shoulder the brunt of it. In fact, women often find themselves caring for their in-laws, as well as their own parents. The stress and strain simply becomes too much for a marriage to bear.

Likewise, children are neglected – neglected, just when they need so much attention, as they are affected by Grandpa's confusion or Grandma's frailty. This is the era of the 'sandwich generation,' those pulled between the demands of children and aging parents. Who will get mom's time – an anguished teenager, a frail parent or a disgruntled spouse? About 40 percent of caregivers have children under 18 living at home.

Financial implications

The average cost of nursing home care in the U.S. (as of March, 2006) is more than \$70,000 a year. That price tag does not include the cost of medications or rehabilitative therapy. In certain areas, the price soars even higher. In New York City, for example, the average cost of nursing home care is now more than \$140,000 a year.

Assisted living facilities generally cost much less than nursing homes (nearly half). The cost of in-home care varies widely, depending upon the needs of the elderly person and the availability of family members. Generally speaking, in-home care costs far less than nursing home care, unless a person needs 24-hour care, including several hours of nursing care.

Medicare covers almost none of this, and most older people do not have long-term care insurance. Instead, people pay these bills themselves until they are impoverished, at which point they qualify for Medicaid. Family members often pitch in, so not only is the elderly person impoverished, but often the caregiver's personal finances are strained as well.

Obviously, long-term care is an enormous financial burden for families. Those on one extreme end of the spectrum can pay for it. Those on the other end quickly find themselves in the safety net of Medicaid (not great, but adequate). But the vast majority

of families reside in the gap. They have faithfully paid off their mortgages and put aside a reasonable nest egg, only to find their savings quickly decimated.

Caregiving and work

Beyond the obvious financial hit of long-term care, is a less obvious, but just as pressing, issue – the toll eldercare takes on a caregiver’s work life.

According to a study by the National Family Caregivers Association done in 2001, one half of all caregivers are employed. The statistics on how they handle this vary, but it is clear that many quit work completely, and between 50 and 70 percent make adjustments at work, largely by cutting back their hours. The vast majority make phone calls and send emails related to eldercare during the workday, and virtually all of them are distracted, preoccupied and exhausted at work because of their caregiving duties.

A 2006 study by MetLife Mature Market Institute estimated that the cost of eldercare, in terms of lost productivity to U.S. businesses, was nearly \$34 billion a year.

Behind the statistics are real-life stories:

Ann’s father lives with her. He has mild dementia and recently lost most of his eyesight. He wakes frequently during the night. He needs someone to watch him all the time, as he hallucinates, and is also likely to fall down the stairs or wander out into the street. Ann has a 15-year-old daughter and cannot afford to leave her job. But hiring someone to stay with her father during the day will cost more than she earns. She is frazzled and frightened. She hasn’t had a full night’s sleep in weeks. She’s put together a patchwork of help, but it is a temporary fix. She doesn’t know what to do or where to turn.

Lindsey lives in Illinois and her mother, who is 83 lives in Mississippi. As an only child, the onus of care falls to her. Lindsey has used up all of her sick days and personal days visiting her mother, who recently had heart surgery. She knows that her mother will only grow weaker and more frail. Lindsey has one child at home and one in college. She is worried about the future. She is worried how she will care for her mother and how all this will affect her work and income. As someone who works in sales, and is dependent upon commissions, she cannot afford to miss work.

Cheryl is a social worker in a school. Her mother lives nearby and has early Alzheimer’s disease. On several occasions, Cheryl has had to stop what she’s doing, walk away from troubled students, to deal with a crisis concerning a mother. She also has a child at home. She worries what she’ll do as her mother’s illness grows worse, how she’ll continue to work, how she’ll pay for her mother’s care. She says, “How do you begin to prioritize things in your life?”

Mary’s in-laws moved in recently. She and her husband pay all his parents’ bills. She also worries all day from work – are they eating, are they okay alone, are they safe, how will we continue to pay for this. The emotional and financial pressure, along with the lack

of privacy or free time, has put so much strain on their marriage that Mary doesn't think they will survive it.

A CRITICAL NEED

I typically address caregivers, not policy-makers, and when I do I make two main points. One, plan ahead. If we could simply get people to think about all this sooner, to plan for it even a little bit, we could ease the strains enormously. Unfortunately, most people approach eldercare one crisis at a time.

But the second point is the one I want to stress to this committee today: Take care of the caregivers.

We've all heard flight attendants instruct us to put on our own oxygen masks before assisting someone else. They say this for a very good reason: You can't help someone else if you are suffocating. Caregivers need oxygen.

Although there are dozens of them, I don't think we don't need studies to tell us that caregivers who have support, who have access to services, and who take breaks, take better care of their elderly family members, stay at this task for a longer period of time, and keep their loved ones out of institutions. They also are less apt to be depressed, sick and impoverished themselves.

Most caregivers, however, do not have such support. They do what they can until they burn out, until they are physically sick, clinically depressed, unemployed, abusive, financially-strained, and/or contemplating divorce, and then they reluctantly put Dad in a nursing home.

In my experience, several things determine whether an elderly person enters a nursing home. Dementia, immobility, and incontinence are obviously huge factors. But the caregiver's health and emotional well-being are also deciding factors.

Caring for the caregiver is a win-win situation. Families want to take care of their aged relatives. Elderly people want to stay in their own homes. And we, as a society, want to avoid the enormous expense and questionable care associated with institutions.

THOUGHTS ON POLICY

I am not a policy person, but I have studied this issue for nearly 15 years, so there are a few things that come to mind.

One, don't reinvent the wheel (or, in this case, the wheelchair). It would be helpful to fully review what's out there, what works, why it works, and what doesn't work. Beyond the larger programs – PACE, Beacon Hill Village, consumer-directed programs, care voucher programs, California's Caregiver Resource Centers, Oregon's Lifespan Respite

Program, Pennsylvania's Family Caregiver Support Program, etc., etc. – there are hundreds of small-scale projects underway.

Any review should look internationally, as well. Israel, for example, has introduced a number of new programs in recent years – a network of day care centers, intergenerational housing programs, wide-scale volunteer programs, counseling centers, and public insurance programs.

Overall, caregivers need support, counseling, education, respite, adult day services, transportation and meal delivery programs, companions and aides, and homemaker and handyman services.

We also need:

Early intervention in order to assist caregivers before they burn out.

- Help navigating the current system, which is impossibly fragmented and complicated.
- Assessments of caregivers when the elderly are assessed (as they often are by medical clinics, community case workers, hospitals and nursing homes)
- More services in rural areas, which are often lacking programs
- Volunteer initiatives that put both young people and old people to work caring for those in their communities
- Intergenerational programs that do not sequester the elderly. Integrating our seniors into our lives and communities is essential for any program.
- A holistic approach that addresses the numerous needs of both the caregiver and the elderly person

The population of elderly people is growing rapidly and the needs of this population are greater than ever before. We need to support our family caregivers now so that we are not left supporting this large population of elderly up the road.

Thank you.