

Introduction

The United States lacks a long-term care system. The closest it has is Medicaid, a safety net program for the very poor. According to the U.S. Department of Health and Human Services, at least 90% of older persons receiving help with activities of daily living (ADLs) in 2011 relied on some “informal” care, from family members and friends. About two thirds relied on only informal care. Family and friends collectively provided 75–80% of total care hours in non-institutional settings (Spillman, Wolff, Freedman, & Kasper, 2014). Help with ADLs involves one or more basic daily functions, including dressing, self-feeding, grooming, toileting, bathing, transferring (e.g., into and out of bed) and moving from one place to another.

Keeping an older adult in the community using round-the-clock formal care is an expensive proposition. Community Medicaid will pay for some custodial care at home, but rarely beyond six hours daily. With most states in budget crisis, even limited services are difficult to access and long waiting lists are common. When paying privately for care is unaffordable, family members assume the burden by default. Older adults without available family help are consigned to nursing facilities or risk health and safety by remaining alone in their homes.

Most family caregivers today are motivated by an intense desire to keep loved ones out of the understaffed and under-resourced nursing homes they see as little more than warehouses for disabled and demented older adults waiting to die. Even when they can afford elite nursing facilities, family members still face the emotional distress that inevitably accompanies this late-life transition. It is not surprising that the number of people residing long-term in nursing homes has dropped over recent decades, even as the number of older adults needing care at this level has remained the same (Redfoot & Houser, 2010).

The situation is about to get worse. The tidal wave of baby boomer retirement is upon us along with the “birth dearth” that followed. Family caregivers, adult children in particular, face bleak prospects. Adult children of boomers, Generation X and early Millennials, will be dealing with work obligations, their children’s college expenses, the effects of the recent recession, and ongoing economic stagnation. They will be hard-pressed to take on the extent of caregiving that will be needed by the huge boomer generation.

This book makes the case for recruiting and training millions of additional personal care aides as boomers age into their 80s and face chronic illness and severe disability. The aides will be needed to assure safety and emotional well-being and to relieve overburdened family members. They should be deployed into private homes, senior residences, and even nursing homes to ensure quality person-centered care for up to 24/7. Medicare, or a new insurance program, should make such assistance universally available.

The 2030 problem

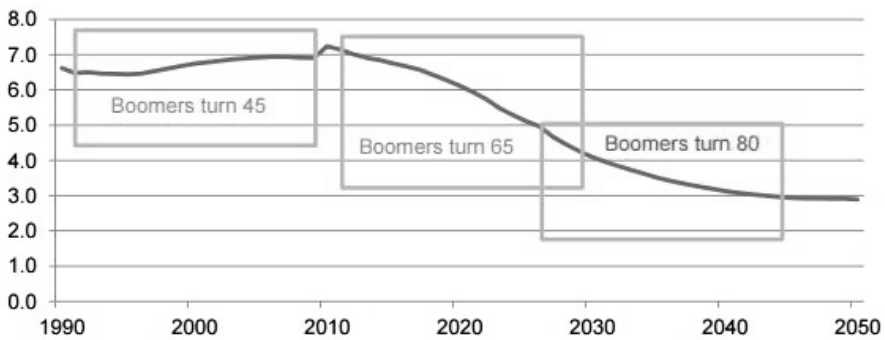
We are well aware that the retirement and aging of baby boomers over the 40-year period from 2010 to 2050 will present problems to advanced nations, including the United States. Some call it the Silver Tsunami. Demographers, epidemiologists, economists, and sociologists have been digging into the numbers and a large literature has emerged describing the many potentially serious social and economic problems that are likely to accompany a rapidly aging population. The scale and pace of aging is unprecedented for modern advanced societies and is already reaching into developing nations, notably China.

This book argues that most of the analyses and predictions used in policy discussions in the U.S. underestimate the extent and depth of what we will be facing. In particular, they do not appreciate the implications of what some refer to as the “2030 problem”. 2030 is when retired boomers start becoming octogenarians in large numbers. Between 2030 and 2050 the size of this “oldest old” population will explode, increasing 3.5 times compared to its size in 2010, becoming by far the fastest-growing segment of the population. The age 80+ population in the United States will grow from 11 million in 2010 to 18 million in 2030, and 35 million in 2050, while the overall population increases only marginally (Redfoot, Feinberg, & Houser, 2013).

Who will care for the oldest old boomers? The birth dearth that followed the postwar boom has created an acute problem. In 2010 there were 7.2 available family caregivers 45–64 years of age for every American 80 years of age and older. According to the Public Policy Institute at the American Association for Retired Persons (AARP), using census-based projections, by 2050 there will be only 2.9 family caregivers for this population, a drop of over 50% (Redfoot et al., 2013). As the number of

oldest old accelerates upward, the number of available family caregivers accelerates downward (Figures 1 and 2). Husbands, wives, sisters, and brothers will have increasingly limited roles as caregivers as they, too, reach very old age. It will be the small cohort of middle-aged children of boomers facing this caregiving nightmare in 2030-2050.

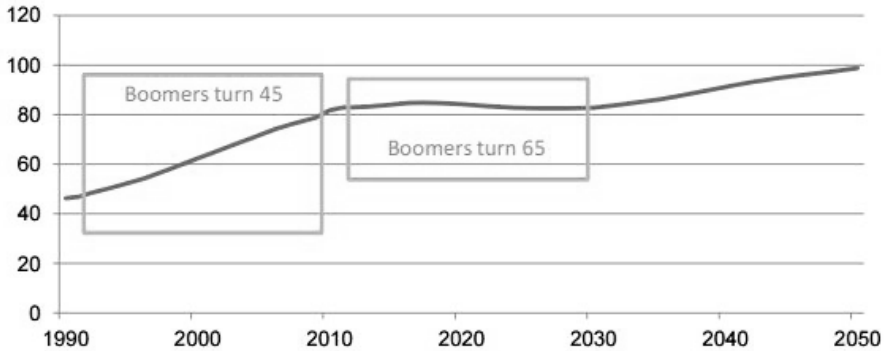
Figure 1. Caregiver support ratio, U.S.



Source: AARP report “The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,” by Donald Redfoot, Lynn Feinberg, and Ari Houser. Calculations are based on REMI (Regional Economic Models, Inc.) 2013 baseline demographic projections. Reproduced with permission from the AARP Public Policy Institute.

Note: The caregiver support ratio is the ratio of the population aged 45–64 to the population aged 80-plus.

Figure 2. Projected age 54–65 population, U.S. (in millions)



Source: : AARP report “The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,” by Donald Redfoot, Lynn Feinberg, and Ari Houser. Calculations are based on REMI (Regional Economic Models, Inc.) 2013 baseline demographic projections. Reproduced with permission from the AARP Public Policy Institute.

Will the 2030 caregiver problem become a crisis?

Most analysts and policymakers agree that an aging society creates problems. Many focus on potential labor shortages and the pressure placed on social security systems. Social Security and Medicare are expected to develop solvency problems that suggest, to some, a need for sacrifice in the form of retirement age increases, reduced benefits, and increased payroll taxes on younger workers.

Most believe that such problems, while troublesome, will be tractable. Boomers, they say, are healthier and wealthier than prior cohorts. With fewer boomers doing manual labor, they will work into their 70s, be healthier in their 80s, and suffer only a small window of disability before death. Such a “compression of disability” will mean that fewer caregivers will be

needed, relatively speaking. Retiring later will help prevent labor shortages, they say, and a slow growth economy could have salutary effects by mitigating resource depletion, global warming, and uncontrolled immigration. After 2050, demographics will rebalance and we will be in a position to focus on quality instead of quantity of growth. While an aging society is not ideal, they say, there is no need to panic.

A major crisis

This optimistic assessment ignores some important factors that will move front and center by 2030 and turn a problem into a crisis. The first is the sheer magnitude of the problem. Compression of disability is at best a questionable assumption and if the extension of lifespans is occurring mainly through management of chronic conditions, this may only prolong the period of disability, dementia, and frailty for many of the oldest old. Any compression effect will be dwarfed by the sheer scale of the overall problem.

The second factor is the lack of long-term care insurance and a less-than-anticipated savings cushion for boomer retirees. The third is the inadequacy of institutional and community Medicaid.

A fourth and often-ignored factor is the reality of the caregiving process, its intensity, and its effect on family caregivers. Middle-aged children of boomers, many of whom will be “sandwiched” between managing their children and their parents, face a caregiving burden potentially much greater than that being assumed by current family caregivers. The emotional, physical, and financial strain will be overwhelming to many.

The seriousness of this last factor is best captured by considering the caregiving needs of those with dementia, the most stressful and demanding

type of custodial care. According to the Alzheimer's Association (2014a), about 15 million family members and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's disease and other dementias in 2013, over 1,000 hours of care per caregiver. With dementia prevalence expected to triple by 2050 (Hebert, Weuve, Scherr, & Evans, 2013), this could rise to over 50 billion hours.

The dementia problem goes to the heart of the impending crisis. Older adults in the more advanced stages of dementia cannot be safely left alone, yet they often have behavioral problems that challenge even the most patient caregiver. Who will care for these elders? Will boomer children be forced to leave the workforce in large numbers? How many boomers will live alone with dementia or severe disability, or be warehoused in under-resourced nursing homes?

The moral imperative of caregiving

As in many other societies, there is an expectation in the U.S. that, regardless of what the government may or may not contribute, it is up to children to care for their parents and other family members when they are unable to care for themselves. Most will institutionalize a parent only under the direst circumstances. Even then, they will suffer continuing psychological stress sensing the depression, anxiety, and anger their loved ones feel upon entry into even the best of nursing homes.

The moral quality of this expectation keeps family caregivers from complaining and leads them to take on extraordinary burdens. The suffering is in silence. The silence, unfortunately, keeps long-term care out of the public spotlight and low on the policy agenda.

Chapter One describes the scale of the impending 2030 caregiving problem in more detail. It discusses specific characteristics of the boomer generation, including divorce rates, childlessness, and retirement finances. It also examines characteristics of boomer children, including their economic and family circumstances. It finds that the capacity of these children to contribute to the care of their parents will be limited.

Chapter Two discusses boomer health, especially risk factors for disability. It considers positive trends that appear to be leading to a compression of disability. It also considers the worrisome possibility that, due largely to the effects of obesity, stress, and associated metabolic and neurological disorders, levels of care need for boomers when they become the oldest old may, in fact, be worse than anticipated. Of particular concern is the possibility that those disabilities requiring the most intensive caregiving, namely dementia, mobility impairment, and frailty syndrome, will become more prevalent than projected. Dementia, in particular, will be the source of the greatest caregiving concern.

Chapter Three examines family caregiver burden, focusing on its psychological and emotional impact. Family caregiving is, in itself, a burdensome enterprise with significant economic and social effects. Dementia, and the presence of especially negative mood, anxiety, or agitation in an older family member can amplify caregiver distress, impacting the psychological and physical well-being of the caregiver.

Chapter Four discusses the capacity of the nursing home industry in the U.S. to deal with the impending crisis. Real and perceived problems have created a poor public image for these institutions, creating an intense aversion to nursing home placement. This, in turn, has led to a redirecting of public funds away from nursing homes, further worsening their lot, and toward the recent movement for de-institutionalization and “culture change”. Nursing homes will clearly have to play a part in a world

experiencing a rapidly declining family caregiver population, especially for those suffering from dementia and other conditions requiring round-the-clock care. Can we deal effectively with their shortcomings?

Chapter Five looks at innovations and reforms either underway or proposed for the nursing home sector. Dementia “special care units” show promise for providing the kind of care required for those with moderate to advanced Alzheimer’s disease and other dementias. The “Green House” model, promoting small nursing homes that provide person-centered care in home-like environments, has shown some success in overcoming the sterile, medicalized environment of traditional nursing homes, and increasing resident satisfaction. Similar culture change has also been proposed for the larger nursing homes that serve poor, severely disabled, Medicaid-dependent populations. Even promising reforms struggle with cost factors, however, and currently serve mostly the more affluent. Changing the culture of traditional homes will require confronting significant resource shortfalls, especially in direct care worker staffing.

Chapter Six considers “assisted living” and its potential to mitigate the 2030 crisis. The demand for long-term care services in the community has led to the emergence of a large, for-profit assisted living industry. In the current system, however, services are aimed primarily at those who can afford to pay privately. Efforts to include middle- and low-income residents are underway but face formidable challenges.

Chapter Seven continues the discussion of alternatives to nursing homes and considers formal in-home care. As with assisted living, this kind of care is too expensive on a private pay basis. Since it is still less expensive than assisted living and nursing homes, however, and is clearly the preferred option for older adults and their families, there is considerable interest in finding ways to fund new programs that allow older adults to “age in place” in their homes and communities. These programs, including

the successful Program for All-Inclusive Care for the Elderly, or PACE, face a number of obstacles and are already feeling the effect of state and federal efforts to hold down costs.

Chapter Eight focuses on policy solutions and concludes that only a federally-financed universal long-term personal care insurance program can make a serious dent in the problem. This would be, in effect, adding personal care services to Medicare. Millions of personal care workers could then be deployed to provide up to round-the-clock custodial and basic medical care to disabled older adults, in their homes, in assisted living facilities, and in nursing homes.

Such workers are expected to be in short supply over the next decades. They will need to be compensated at higher rates and have better working conditions and training. Personal care aides must become respected paraprofessionals.

Medicare became a reality 50 years ago when the vast majority of citizens, across the political spectrum and all social classes, saw that improving the health of the older population would benefit society at large. Adding long-term personal care to that benefit is long overdue and essential to addressing the 2030 crisis.