

Faces of Long-Term Care: A Look in the Mirror

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Introduction: The Risk We All Face

Frank took great pride in his independence. He had been a widower for nearly 3 years, but had maintained his home and continued to participate in the activities that kept him busy before Sally had died. His greatest fear was becoming dependent on his children. Unfortunately, his fear was realized when at age 79 he had a stroke. He had shown signs of confusion prior to the stroke, but these problems would become more significant thereafter. Frank was amazing however. He recovered most of his function after rehabilitation and was able to walk (with a cane), talk, and perform most activities of daily living on his own. Given his level of functioning it seemed to his kids that he was well-suited to moving into an assisted living facility.

Zoë was a great swimmer and really excelled at the 100 meter IM. In high school she was captain of the swim team. By the time she reached college, however, she had lost interest in competitive swimming, but she still swam laps almost every other day. All of that came to a dramatic end when at age 22, she dove headfirst into the lake. Normally a favorite watering hole the lake was considerably lower due to a drought over the past two years and a recent dam release. Now a quadriplegic, she could no longer do very much for herself.

Jean was always in charge; she was also the family worrier. As the second oldest of four children, she was the one who seemed to worry the most about what she would do if her parents needed help. After all, they lived on the other side of the country. Although her concern remained, it was no longer her dominant concern. At age 46, Jean had been diagnosed with MS. By the time she was 51, she was forced to give up her teaching career and now at age 53, she did not know how her family was going to cope with her declining abilities. She can still get by on her own using a walker, but increasingly she was spending more of the day in a wheel chair. Eating was getting even harder to do, as was everything else. Looking back she could differentiate the dramatic decline

in her strength, function and of course the acceleration of her tremors. She thought the medication was helping, but now, in retrospect she has come to realize that that had been wishful thinking.

Finding Common Ground

Frank, Zoë, and Jean have relatively little in common. They are not the same age, nor do they have the same needs. They are, however, three people who need health care and a wide array of ancillary services. Some might call these ancillary services supportive care; others call it long-term care. Regardless of what it is called, this assistance is necessary for these individuals to function on a day-to-day basis to avoid being hospitalized.

Arranging for this type of assistance becomes the responsibility of the people surrounding Frank, Zoë, and Jean. For most family this is an emotional and physical struggle. Help and information are not always available, consistent, or effective, leaving families in the position of figuring out what to do, and unable to be sure that what they are doing is right. It is families who are responsible for arranging, organizing and providing most of the care while at the same time dealing with the anxiety and guilt associated with trying to figure it all out.

The Risks We Face

From opinion surveys most people seem to equate long-term care with old age and nursing home care. This general sense is not quite right. About 60 percent of persons who need long-term care are age 65 or older and nearly 40 percent are younger. Further, while a substantial share of long-term care dollars are expended in nursing facilities, most people who need long-term care do not live in a nursing facility. While there is no doubt that the risk of needing long-term care increases with age, even most persons age 85 and older who need significant levels of long-term care do not live in a nursing facility.

At younger ages, congenital defects and accidents are dominant sources of risk. At middle age, or between ages 45-55, degenerative diseases contribute to our risk. In older ages, particularly after age 70, we are subject to the risk of many of the same degenerative diseases that can afflict us at younger ages, plus a few more. Multiple chronic health conditions and frailty can “gang-up” and further diminish our capacity and increase the likelihood of needing long-term care, particularly after age 85.

Nationally, about three percent of babies are born with birth defects.¹ The impact of these birth defects varies. At one extreme, Rett Syndrome is a rare form of autism and a birth defect that affects about 1 in 10,000 females. Sufferers often live into their 40s and 50s, but with very limited functioning all of their lives: it is unlikely that they are able to walk or talk, and may be unable to feed themselves.²

In 2005, about one out of twelve Americans, or over 21 million people, sustained a non-fatal but disabling injury.³ While this figure includes many injuries leading to temporary disabilities, it also describes the permanent disabilities that would lead to long-term care needs. About 13 percent of non-fatal injuries are serious and can lead to among other things spinal cord damage and brain injuries.⁴ Car accidents, for example, contribute to about 10 percent of non-fatal injuries.

In addition to accidents, younger people can also have a stroke, develop cancer, or acquire many rare degenerative diseases such as Multiple Sclerosis or Parkinson's disease. While strokes are a leading cause of adult disability, with the highest risk for those above age 55, strokes can occur in teenagers and children. Although such strokes are uncommon, the effects are devastating and, unlike strokes in adults, can result in additional conditions such as cerebral palsy, mental retardation and epilepsy.⁵ Cancer can and does happen at any age. About one in two men and one in three women will develop cancer during their lifetimes, and 23 percent of those individuals will be under age 55 when they are diagnosed.⁶

Multiple Sclerosis (MS) affects about 300,000 Americans, and can either be mild or lead to permanent disability requiring long term care. Although the severity of this disability tends to increase with age, the onset of MS usually takes place between ages 20 and 40.⁷ Parkinson's disease causes deterioration that eventually leads to disability. While most people with Parkinson's disease develop it after age 65, 15 percent of patients are diagnosed when they are younger than 50.⁸

Arguably among the cruelest of diseases, particularly for caregivers, Alzheimer's disease reflects one of many different types of progressive brain disorders that gradually destroy a person's memory and ability to learn, reason, make judgments, communicate and carry out daily activities. As Alzheimer's disease progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations. These changes can be terrifying to the caregiver and quite sad when the person with the disease no longer recognizes their spouse or adult child. It is estimated that more than 5 million people in the United States have Alzheimer's dis-

ease. Most are over the age of 65; however, between 200,000 and 500,000 people are under age 65 with early-onset Alzheimer's disease and other dementias.⁹

Diabetes is now among the fastest growing chronic conditions. About 800,000 people are diagnosed every year and more than 16 million people were estimated to have diabetes in 1999.¹⁰ With obesity on the rise, diabetes rates are expected to increase dramatically, perhaps reaching epidemic levels.¹¹ While diabetes per se does not lead to the need for long-term care, its role in affecting other health conditions and the difficulty in treating it particular for people with long-term care needs makes diabetes a major complicating factor. Diabetes can lead to death (it is the seventh leading cause) but it is more likely to lead to heart disease, stroke, blindness, high blood pressure, kidney disease, and amputations. These complicating factors can result in the need for long-term care; and just as insidious, a substantial percentage of long-term care patients suffer from Diabetes.

All told about 10 million people, or nearly 5 percent of the population, need long-term care. Most (81 percent) live in the community and about 19 percent live in nursing facilities.¹² Collectively, then, Frank, Zoë, and Jean represent tiny proportions of the population. At ages 79, 22 and 53, respectively, many more people who need long-term care are Frank's age, but many are also Jean's age. Fortunately far fewer are Zoë's age, but unfortunately Zoë is not alone.

This suggests that parents, spouses, siblings and children are involved with the worry, disruptions and effort necessary to arrange and provide needed care. While 10 million people need long-term care assistance, the lives of perhaps another 20 to 25 million people are affected.

Over a lifetime, each and every one of us faces the profound risk of worrying about, providing, or needing long-term care. The risk seems imperceptible, perhaps until much older ages -- particularly after age 75. By the time we are 85 or older, more than five out of eight of us, or 64 percent, need long-term care.¹³ About 14 percent of us will be living in a nursing facility and another 51 percent will be living in the community. Among the population age 85 or older, living in the community, about 12 percent have limitations of three or more Activities of Daily Living (ADLs). Limitations in ADLs reflect the inability to undertake daily tasks that are essential such as the ability to eat, dress, bathe, get out of bed, or use the toilet.

The following table compares people age 85 or older living in the community with limitations in three or more ADLs with persons the same

age without any limitations. This population is less likely to be married but more likely to have been to an emergency room and to have home health care visits. Although persons age 85 or older with limitations in three or more ADLS were more likely to have had a physician visit, those without limitations were more likely to have had 11 or more physician visits per year.

Table 1.
Population age 85 and older

	Limitations in 3 or more ADLS	No Limitations
	<i>Percent</i>	<i>Percent</i>
Marital Status		
Married	4.83	28.57
Not Married	95.17	71.43
ER Visits		
None	64.89	81.05
1 or more	35.11	18.95
Home Health Visits		
None	46.89	83.68
1-100	18.6	14.48
101 or more	34.52	1.84
Physician Visits		
None	7.71	14.5
1-10	79.85	67.7
11 or more	12.44	17.8
Dental Visits		
None	82.77	72.07
1 or more	17.23	27.93
Income		
Mean	\$26,892	\$19,436
Median	\$12,838	\$13,491

SOURCE: Tabulations from the Medical Expenditures Panel Survey, 2000.

Given the difficulties of getting someone with limitations in three or more ADLS out of the house, it is not hard to imagine that getting to the physician is a significant undertaking. Perhaps, not surprising, those with limitations were less likely to visit the dentist.

Although the median incomes of the two groups were similar, average income among those with limitations in the community was slightly higher than those without limitations.

Figuring Out What to Do

It is hard to convey just how terrifying and difficult long-term care is to address. Perhaps the experience of experts can help put this in context. Rosalie and Robert Kane along with Robert's sister Joan founded a group of health and long-term care professionals outraged over the inadequacies they experienced from their own experiences as a patient or caregiver. The Kane's are well known among academics and researchers. Robert Kane, MD and his wife Rosalie Kane, Ph.D., through their research at The Rand Corporation and the University of Minnesota, have contributed volumes to the academic research literature and as Professors they have helped to train a cadre of researchers, academics, and professionals. And yet, when it came to their own mother they were frustrated at how difficult it was to make the system work for her. As an outlet for their frustration and concern for others they founded Professionals with Personal Experience in Chronic Care (PPECC). As stated on their website: "Our message to policymakers and health system leaders—If professionals working within the health care system are having serious problems getting care for themselves and their families, then the system is failing in a major way."¹⁴

As Robert and his sister Joan writes:

Each step was harder for all of us. Despite our best efforts, nothing about this experience reflected the way she wanted to end her life. All the way through this depressing experience we kept asking ourselves, "If this is happening to us, who know how the system works, what must it be like for those who enter it uninformed and ill prepared?" Looking back over this experience it was not the way any of us would have wished it. Mother lived the life she dreaded. Joan found herself never able to do enough and miserable watching her mother decline in front of her. Robert was frustrated with his inability to make the situation work. All of the theories about how different types of care were supposed to respond to changes in an older person's life simply fell apart, despite his best efforts to

find the best providers of care and to help them develop effective approaches.¹⁵

Zoë, Jean and Frank, do not have within their families or friends any physicians or other professionals who can help them navigate the confusing worlds of medicine, chronic care, or long-term care. They and their families have, like most families, been thrust into this situation without preparation or assistance, forced to learn about options as well as the ways and means of long-term care by trial and error. As we will explore in the next section, for Zoë's parents and Frank's children, the learning curve was very steep; for Jean and her family, it was a bit more gradual.

Some of the Faces of Long-Term Care

Frank

In many ways Frank lived a charmed life. He fell into his career, made a relatively good living, had two easy to raise children, and played golf a lot. Frank loved golf and fortunately golf had been good to him. Much of his career was enhanced by it. Frank was very active, very social, and in great physical shape. He played golf almost every weekend and prior to retiring often once a week. After retiring he played three or four times a week. When it comes to golf few days were too cold, too wet, or too hot for Frank.

Frank's first real experience with the health care system came when his wife died. Even then, Frank's experience was relatively easy. Frank would never have to test his mettle against the rigors of caregiving. Sally passed away within three weeks of getting sick, and she spent more than her last two weeks in the hospital in the Cardiac Care Unit. She had nurses, nurse's aides, attending physicians, and resident physicians attending to her medical condition. Frank stood by, a bit confused, very scared, but with little that he could do but to wait and worry.



After the funeral, Frank's kids were worried, but Frank really picked up where he had left off. His kids were amazed by his resilience and soon their worry subsided. It would be another six years before his kids would reflect back upon this time and wonder. Frank just seemed too serene.

Frank did have a thyroid problem, hypertension, and arthritis. He took 4 different medications; 3 pills in the morning, and 2 pills right after lunch. But except for the stiffness of his arthritis and the occasional doctor visits, he had been in remarkably great health. He still golfed, drove a car, and was completely independent up until the time he had the stroke. After Sally died, he ate more of his meals at the senior center or at the golf club and rarely did more cooking than boiling water or setting the timer on the microwave.

When he had the stroke, he was very fortunate. He was visiting with his doctor for a routine visit. They were able to attend to him and call an ambulance minimizing the damage significantly. He ended up staying in the hospital for 9 days. By day 4, he was receiving speech, occupational and physical therapy. He learned how to walk with a walker and worked hard to get his right arm functional again. When he left the hospital his speech was still slurred, but he was comprehensible. In addition, he had lost his ability to control his bladder.

The Discharge Planner and the Doctor arranged for home health care visits to continue the therapy, but within a few months home health care coverage would end and his children would have to start taking him to therapy twice a week. Concerned about his living arrangements, Frank went home with his son and daughter-in-law. They took turns watching him and learned about his exercises from the therapists. Frank needed to wear diapers and started taking a new medication to help him control his bladder.

Within 6 months, Frank, who had been at death's door, was walking with a cane. His speech was nearly as good as it had been, and although he regained much of the function in his right arm, he was never going to play golf or drive, again. He was able to stop wearing diapers during the day, but did so at night, just in case.

His children found him an assisted living facility nearby and convinced him to let them clean out his house and put it on the market. Frank moved into the assisted living facility where all seemed to be going well for another 11 months. However, it was clear that Frank was just not the same anymore. He had lost some of his zest for life and he seemed to repeat himself a bit more and at times he seemed confused.

The medication he was taking to help improve his neurological functions was affecting his blood pressure.

In July he went into congestive heart failure and was rushed to the hospital when he complained he could not breathe. This occurred 2 more times over the course of the next year. Each time he returned to the assisted living facility he seemed even more confused and more agitated. The nurse's aides at the assisted living facility were nervous about him living there and felt he needed to be watched more closely than they were able. After the third episode, the assisted living facility asked Frank's son to find Frank a new home. They told him that they were no longer the right place to take care of him. Hiring a full-time nurse's aide to stay with Frank in the assisted living facility might have been an option, but the assisted living facility did not suggest this and Frank's son did not understand enough to even ask.

Frank's kids just did not know what to do; nobody wanted Frank to move into a nursing home and so Frank moved back with his son. This time his son and daughter-in-law converted their dining room into Frank's bedroom. Since Frank's kids work full-time, they supplemented their care with an aide from the local home care provider. The aide would come about 9:00 am to watch Frank, make sure he eat lunch, took his afternoon pills, and work with him on his exercises. Unfortunately, agency concerns about liability prohibited the aide from taking Frank to his physician or physical therapy visits. On most days this arrangement seemed to be working out well; but occasionally the aide would not show up and someone would have to decide to either stay or come home from work. Someone always had to take time off to take Frank to his cardiologist, his neurologist, or his internist or to see the physical therapists.

Frank's son and daughter-in-law had no idea that Frank was in the early years of Alzheimer's disease. Frank's children had come to understand the consequences of the stroke and they thought this was contributing to his risk of congestive heart disease, but an underlying co-morbidity that had yet to be diagnosed was going to turn their lives upside down.

One morning Frank left the house. The aide had come around 9:45 am but could not find Frank in the house. She assumed he was out back in the garden, but she did not bother to look until after she had prepared lunch. It was only then that she called Frank's daughter-in-law. Frank's Daughter-in-law then called the police but while the dispatcher was sympathetic he said there was not much he could do unless there were signs of foul play. After all, he was, as far as everyone knew a competent adult.

Frank's son and daughter-in-law left their respective offices right away and started searching the area in their cars. Although it was already past 5:00 pm, Frank's son was relieved when he saw Frank walking down the street. Frank could not explain where he was going or why he had left the house. Frank's son could not comprehend what was going on and was now beginning to get angry. How could his father have scared him like this; especially after all he and his wife had done!

Although Frank lived a good life, he was not wealthy. The membership in the golf club was always more important than saving for retirement. He had Social Security, a small pension, and a modest amount of savings. His Social Security and his pension was about \$1,500 a month. The sale of his home had nearly tripled his savings. The Assisted Living Facility, however, not only consumed his monthly income but also drew his savings of \$300,000 down to \$186,000. Hiring an aide to be with Frank, Monday through Friday, from 9 am to 6 pm turned out to cost nearly \$4,000 a month. Even at this level of assistance, Frank's children had to leave work to take him to the doctor. At this rate, Frank who was now age 83, would be fine, as long as he did not need to move into a nursing facility or did not live more than 6 years.

Zoë

Although she does not remember the accident, her friend Melissa will never forget. Melissa was able to get Zoë out of the water. Fortunately she had a cell phone, which she used to call for help. It would be another week before Zoë was conscious. Zoë's family was devastated.



Zoë had been out of college for less than one year. She had been working as a waitress while looking for a job in her career and was living at home. She was determined to pay off her student loans before moving out. Too old to be on her parent's health insurance policy, she was not insured. Zoë's parents had money set aside for retirement, but they too had also borrowed to help pay for Zoë's college.

Zoë's parents were able to use their home equity line-of-credit to finance the refurbishing of the house. A ramp was added to the front door, three doors were widened, and a sunroom off of the living room was insulated and refinished to accommodate a hospital bed, a commode, and the wheel chair. They also bought a van and added a wheel chair lift.

In the hospital Zoë was enrolled in Medicaid, which would cover most of the hospital bill, but Medicaid would only pay for a home health aide to come to the house for four hours a day. Zoë's mother stopped working, and stayed home to tend to her daughter.

The aides from the agency were often late but nearly always showed up. More problematic, however, was the parade of different aides. For most weeks she would see the same 3 or 4 aides, but every six months or so, the 3 or 4 aides she had come to know would be different. Zoë's mother felt it was her responsibility to train each new aide. She also felt it was critical that each aide know who her daughter was.

Zoë's mom, with the help of the aide, would bathe Zoë, clean her catheter, and provide her with her daily enema. It would be years before Zoë's mom would ever leave Zoë alone with an aide, but, when she found an aide she could trust and when she was sure that aide would show up, she would use some of the four hours to attend to her own needs.

Zoë's parents dedicated their lives to their daughter. Zoë's dad read to her every night and stayed with her while Zoë's mom would finish housework, go shopping, and occasionally attend church events. Every day, several times a day, Zoë's parents took turns moving, turning, exercising, and massaging Zoë's muscles. Seven years after the accident, Zoë's friends, including Melissa, stopped coming by. Zoë's dad did not know how they were going to keep up this routine. He and his wife no longer had anything to talk about, except caring for Zoë. He was about to turn 60 and he wondered who would take care of Zoë when he and his wife no longer could.

Jean

In college Jean really took to her early education classes. Her first job would be teaching 4th grade, which she did for a number of years until she found an opening teaching kindergarten. Her experience with 4th graders and now with kindergartners had made it clear to her that the perfect age at which to share and imbue her passion for learning was 3rd grade. The very next year she was able to obtain a 3rd grade class; where she had remained until the combination of teaching, scheduling doctor visits, and the fatigue from the MS or the drugs she was taking for her MS were too much for her.



Jean was now preoccupied by the very real concern of how her family was going to cope with the inevitable next phase of her disabling condition. Intellectually she always knew this day would come, but emotionally and psychologically she had been so preoccupied with meeting each physical challenge that she had not had the time to fully reflect on what this would mean. It took more than a decade for her to begin to see her former self crumbling away and she was terrified.

The Final Chapter

Frank eventually died at his son's home. Frank was able to afford most of the care that was purchased and Medicare covered the hospice care that came in during the last few months of his life. Frank passed away a few months before his savings were likely to expire.

Jean's husband was fortunate. Although he was not able to work part time in his own practice, he sold his practice and then worked part-time for the firm that bought his practice. He sold the practice for essentially twice the accounts receivable; not much given how successful he had been, but then again as a solo practitioner his practice would be worthless if he was not able to continue to work. The acquiring firm did not need his furniture or even his location; they really did not need him. They were doing him a favor.

He took a substantial cut in his salary, but he was able to spend a lot of time at home helping Jean. His children started to borrow more for college, and his youngest child decided to only apply to the state school, even though she had her heart set on a small liberal arts college in another state. He used all of his salary and most of his savings to maintain the house, purchase the supplies and equipment not covered by his health plan, to pay for a nurse and an aide to help him take care of Jean when he needed to work, and the remainder went to supporting his children.

Work was very hard; mostly because it was so hard to concentrate. He needed the work to get him out of the house, but when he was at work all he could do was worry about Jean. Everything was difficult, especially dealing with his health insurance company. He had to fight with them about everything and they covered nothing related to her needs. They covered her doctor bills, but it was a real battle to get them to cover the new electric wheel chair she needed. They were always denying claims, even for her prescriptions, and refusing to pay for this or that. It was becoming a full-time job fighting with them. Everything became even harder when he sold his practice and had to change insurance carriers. He was outraged by their refusal to pay for her diapers and at how ex-

pensive the diapers were compared to the Pampers in the local supermarket.

Jean lived another 2 more years at home; and while her husband had been able to avoid going into debt to pay for her care, he no longer had very much in savings for his retirement. He was able to liquidate part of his Simplified Employee Pension (SEP) without incurring a tax penalty. Earlier he had borrowed against the equity in his home to retrofit the house, but fortunately that loan had been repaid before he had stop working full-time.

When Jean died her husband was 63 years of age. He had \$112,000 in his SEP, and owed 4 more years on the mortgage, a \$160 a month pension from Jean's many years in the public school system and nearly \$400,000 in home equity. He had assumed he would need to have saved \$800,000 in his SEP to be able to afford to retire and wondered when he should file for Social Security.

Zoë had Medicaid coverage, but this turned out to not be enough. Her parents did the best they could for as long as they could, but eventually it all become too much physically and emotionally.

Reluctantly Zoë's parents decided to move her into a nursing facility. Prior to when Zoë had the accident it had been relatively easy to maintain a middle-income lifestyle and to save for retirement. They struggled with college costs, but if they had both continued to work, they would have recouped from that. When Zoë's mom stopped working, it was harder to pay off the college loans and even harder to save anything for retirement.

About a year after Zoë moved into the nursing facility, her parents filed for divorce. The divorce would take what might have been a small but almost modest amount for two living as one and divided it into two. This meant neither of Zoë's parents would be able to come anywhere close to supporting a middle-income lifestyle.

Although Zoë's mom visited Zoë every day during the week and Zoë's dad spent virtually the whole weekend with her, Zoë had given up. About 8 months later, just two weeks shy of her 45th birthday, Zoë died. Medicaid had paid for much of Zoë's care in the hospital, at her home, and at the nursing home; but the family had also paid a price as well.

What would have helped Zoë, Frank, Jean, and their Families?

Each and every person who needs or who provides long-term care has a unique story to tell.¹⁶ Not unique are the difficulties involved with knowing what to do, knowing whom to turn to, and knowing how to organize, arrange for care and knowing how to provide care. Not unique, even for people with considerable financial means, is the difficulty of finding help from people with the right qualifications and who easily integrate with family caregiving.

People who need long-term care and their families need all kinds of help. They need advice and support. They need counseling, training, and an array of services better integrated with the other facets of their lives. They needed to know what to do, how to do it and they need help getting each of the different parts of the system to work together. They needed a system that does not separate the medical part from the supportive care part of their loved ones' needs. They need providers that are able to respond to the changing needs of each patient. Caregivers need time off and they need to be assured that their financial security is not at risk because of the long-term care needs of their spouse, child, or parent.

In about 15 years, there will be a lot more people like Zoë, Jean and Frank. Furthermore after 2015, the population age 75 or older will have had far fewer children than the current population age 75 and older. Consequently, there will be fewer adult children, like Frank's children, and a shortage of workers relative to the number of persons in need of assistance.

These demographic facets suggest that there is an urgent need to address current and future long-term care issues. Nevertheless, both the public and private discourse on this subject remains inexplicably muted. Lawmakers rarely, if ever, debate public financing mechanisms, and individuals themselves often avoid thinking about long term care. And of those that had become experts: people like those taking care of Zoë, Frank, and Jean, are just too busy being caregivers, too burnt out, and depressed to be of much help in helping the rest of us understand how devastating and inefficient the long-term care system can be.

Denial, Confusion, but Few Options for Pooling Risk

Frank, Zoë, and their families had never thought about or addressed the question of financing long-term care. Only Jean had even thought about it; but of course her concern was that of her parents not of her. It

seems that most people do not envision themselves growing old, getting sick, losing independence, and needing care. This seems quite natural given our predilections towards independence from the day we are born.

In a series of focus groups, for example, conducted with workers age 40 and older, participants imagined themselves aging vibrantly and dying quickly.¹⁷ In another study, focus group facilitators asked why pre-retirees and retirees were not buying long-term care insurance. From the discussions, the facilitators summarized that participants had "...deeply ingrained denial that supersedes recognizing a need for long-term care insurance." The written summary of the sessions suggested that people were quite realistic in their assessment of the financial risks they face without insurance, yet readily admitted that by ignoring the issue it just might go away.¹⁸

Not surprising then, few people have really considered the possibility of needing long-term care. For example adults were asked in a 2004 survey sponsored by the National Academy of Social Insurance (NASI), "Which of the following statements best describes your planning for long-term care," 37 percent responded, "I have developed a plan to pay for long-term care if I need it."¹⁹ The remaining 63 percent of respondents fell into three other categories: "I do not have a plan to pay for long-term care because I don't expect that I will need it" (23 percent); "I really haven't given any thought to how I would pay for long-term care" (31 percent); and "Not sure" (9 percent).

Other opinion surveys reveal that there is confusion and miscalculation about long-term care. The EBRI Retirement Confidence Survey regularly asks people about whether they had factored the possibility of needing long-term care into their retirement planning or considered purchasing long-term care insurance. Again, the answers were mostly negative. Almost two-thirds of respondents (63 percent) age 45 or older had not tried to calculate how much money they would need to have saved to finance their living expenses during their retirement years by the time they retired. Paradoxically, two-thirds of the respondents (67 percent) expressed confidence that they would have enough money to live comfortably in retirement. Moreover, about half (54 percent) said they were confident that they could finance long-term care expenses. Is this denial, hubris, or a lack of understanding?

Unfortunately, more than half of the respondents (66 percent) believe that the average annual cost of a nursing home was \$25,000 when, in fact, the national average was more than \$40,000 at the time.²⁰ Today the average annual cost for a private room is about \$76,000 a year.²¹ The fact that the majority of respondents were confident that they could

cover long term care expenses is just not consistent with the notion that most had not calculated their savings needed nor had a firm idea what the costs might be.

Denial or lack of inquiry might help to explain why there is confusion about how long-term care is financed. Only 38 percent of adults in a June 2005 Kaiser study were able to correctly identify Medicaid as the primary source of health coverage for low-income people who need nursing home care or home care over a long period of time. About 32 percent thought that Medicare was the main source, 17 percent said they didn't know, and 14 percent named some other program.²²

Survey respondents sometimes report that they had long term care coverage when this did not seem likely. About 31 percent of respondents age 45 and older said they had purchased a long-term care insurance policy. If that were true, the long-term care insurance market would be more than six times larger than it was at the time.²³

Long-term care insurance, however, is among the few options available to pool some of the financial risks of long-term care. Long-term care insurance, however, does not really pool the financial risks of needing long-term care; it pools a pre-determined portion of the financial risk. The amount of risk pooled depends on the choices made at the time the policy is purchased. Policy choices include the specific amount of coverage in dollar terms, whether the benefit amount increases over time, the duration of the upfront elimination or deductible period, and the specific way in which claims for benefits can be filed. While there are many product choices, the products and the tradeoffs between products (even within the same company) are very complex, making it difficult, if not impossible, for most consumers to make an informed choice.²⁴ More importantly, unlike other forms of insurance this is the type of product you buy once. That is, this is in effect a lifetime decision.

After choosing a long-term care insurance policy it is likely going to be too expensive to shop around and change policies. This is because the premium being paid is based on both the amount of coverage chosen and the initial age at which this policy was purchased. Some of the premium covers current risk, but most of the premium is prefunding the premium for future risk. If you purchase a policy at age 50 but change your mind about the scope and depth of coverage at age 60, the cost of changing will be to forgo all of the prefunding that occurred from age 50 to 60 and the premium price for the new policy will be based on an initial purchase at age 60 not age 50. Since the purchaser is now 10 years closer to being at risk of needing long-term care the prefunding period is shorter and hence the premium is larger.

Family Anguish

Not surprisingly, parents do not want to be a burden on their children. Jean and her husband did not want their kids to either delay, suspend or even come home after graduating college to help out; yet prior to her diagnosis Jean had assumed she would be the one to take care of her parents if they needed more assistance. Zoë's parents never flinched at the notion of become her full-time caregivers. Frank was caught in a difficult situation and his son and daughter-in-law were always there for him.

In a 1999 survey, 77 percent of respondents said they were not likely to ask their children if they can move in with them.²⁵ More than half (56 percent) said they were not likely to ask their children for help with everyday needs such as dressing and bathing. About 91 percent of respondents were not willing to ask their children to sacrifice job advancement to care for them. And yet, adult children are vital sources of caregiving and as caregivers have sacrificed job advancement.

Adult children, however, do say they are more than willing to take care of their parents. One survey found that 74 percent of children said they were willing to have their parents move in with them and 77 percent were willing to help with everyday personal needs such as dressing and bathing.²⁶ More than half (69 percent) said they were even likely to sacrifice a job advancement to care for their parents.

Perhaps this disconnect reflects a lack of communication. Frank had never talked to his kids about his wishes – not when his wife was sick, not after she died, nor really after he had his stroke. Their conversations were focused on the problem confronting them at the moment. That was what led them to put him up at home initially, find him an assisted living facility, and then move him home when the assisted living facility no longer could care for him. While Jean worried about her own parents, she and her husband had never thought about the possibility that she might need long-term care before they did. Even while confronting her disease, long-term care was not Jean's dominate concern.

A Pew Research Center survey revealed that while 59 percent of adults had discussed their health with their children in the past year, only 41 percent had discussed their financial situation, and only 34 percent had discussed their preferred living arrangements.²⁷

Preferences for Staying Home

Respondents to surveys about long-term care are overwhelmingly negative towards institutions. The 2004 NASI survey showed that 53 percent of respondents had a “very negative” or “somewhat negative” attitude toward nursing homes, versus 36 percent who had a positive view. In a June 2005 survey by the Kaiser Family Foundation 41 percent of respondents thought that being in a nursing home makes people “worse off” than they were before, while 29 percent of respondents to a Kane and Kane survey of seriously ill persons age 70 or older said they would rather *die* than enter a nursing home.²⁸

Seventy percent of respondents to the NASI survey said it was “fairly” or “very” difficult to find quality nursing home care, and the Kaiser/Lehrer survey reported that 35 percent of people age 18 and older thought nursing homes were doing a bad job in serving residents. In reality, studies of nursing home residents reveal generally high levels of satisfaction.²⁹ Perhaps, this dissatisfaction is far more prominent in the anticipation of care than in the receipt of care.

Nursing homes are associated with a lack of independence, lack of control, financial instability, loneliness, and institutional living. Therefore, it is not surprising that respondents strongly preferred the notion of assisted living facilities to nursing homes. In the NASI survey, 65 percent said they had “very positive” or “somewhat positive” attitudes toward assisted living facilities, and in the Kaiser/Lehrer survey, when respondents were asked to choose between an assisted living facility or a nursing home, 78 percent choose the assisted living facility and only 12 percent said the nursing home.

Frank’s kids did what they could to keep Frank out of the nursing home, even though they did move him into an Assisted Living facility. He was fortunate that his children were able to care for him, since by the time he left the Assisted Living Facility, he no longer had enough money to live the rest of his life in a nursing home. Jean too was fortunate. However, her husband is now at risk financially in his older age. Zoë did, eventually, move into a nursing home, perhaps because she was already on Medicaid.

Government Financing

Government programs currently finance about 66 percent of all long-term care services. In light of this fact and due to the confusion about the role of Medicare and Medicaid in financing long-term care, it is not completely clear if opinions about the role of government reflect an in-

formed or uninformed understanding of the current structure. Nevertheless, most people polled have an opinion about the relative role of government.

The 2004 NASI survey, for example, asked respondents to rate their attitudes along a scale from one to seven, where one was that long-term care expenses were “strictly a personal and family responsibility” and seven was “strictly a government responsibility.” Along that scale, about 28 percent of respondents picked 3 or lower (i.e., more inclined to say that it was an individual responsibility) and 50 percent of respondents picked 5 or higher (i.e. more inclined to say it was a government responsibility); and 19 percent picked 4 which is just slightly above the midpoint between 1 and 7.

Other surveys, even those going back a decade, are remarkably similar to this. In the 1998 American Health Care Association survey, two-thirds (66 percent) of people age 34-52 agreed with the statement “As long as you play by the rules and pay your taxes, government health policy should ensure that families don’t go bankrupt from the cost of nursing home care.” Similarly, a 1993 Employee Benefit Research Institute Survey showed that a comparable percentage (69 percent of the population age 18 and older) indicated that it would support government funded long-term care assistance for older persons, even if that meant an increase in income taxes.

In the 2001 Kaiser Family Foundation/NewsHour with Jim Lehrer survey, three-quarters of adults (76 percent) said that it was very or extremely important for the government to pass a law soon to provide funding for long-term care services aimed at helping frail people to continue to live in their homes.

In the 2004 NASI survey, respondents were eventually told that the only government program that covers a substantial amount of long-term care costs is Medicaid.³⁰ Moreover they were told that to qualify for Medicaid individuals could not have personal assets of more than about two thousand dollars. Unless someone has private long-term care insurance, they must pay the costs themselves until they qualify for Medicaid coverage. Upon hearing this, respondents were asked for their opinion about this system. Nearly three-quarters (71 percent) said this system needs major improvements or a complete overhaul. About one-quarter (23 percent) said the system could use only minor improvements or worked well as it is.

In a follow-up question, 70 percent said that they thought the federal government should do more to help people meet the costs of long-term

care. Moreover, of those who felt this way, 60 percent sided with a statement that viewed this role as tax incentives to encourage people to save more and buy long-term care insurance, but the government should pay for the care for low-income people.

State level surveys consistently support more government funding for home and community-based long-term care services. In a January 2002 survey of AARP members in Iowa, 73 percent of respondents either “strongly supported” or “somewhat supported” increasing funding for home and community-based long-term care services through the Iowa Department of Elder Affairs.³¹ Only 19 percent “strongly opposed” or “somewhat opposed” an increase. In a separate survey of Iowa adults 18 or older, 59 percent thought that there was not enough money in Iowa’s health and long-term care budget, and 80 percent would “strongly oppose” or “somewhat oppose” cutting funding for such services.³²

Similarly in Michigan, 77 percent of registered voters polled said there was “not enough” funding to meet the need for service and ensure quality of health and long-term care in Michigan.³³ The vast majority (95 percent) of respondents said it was “somewhat important” or “very important” to maintain current funding levels for Michigan health and long-term care services, and 78 percent of respondents “somewhat supported” or “strongly supported” increased funding in Michigan for home and community-based care services. About half (54 percent) of respondents said they found it “very difficult” or “fairly difficult” to find information about government long-term care programs and services.³⁴

Survey respondents indicate that voting patterns might be influenced by a candidate’s stated position on long term care funding. More than half (61 percent) of Iowa survey respondents said that a political candidate’s position on expansion of home and community-based long term care funding would influence their voting choice. Only 3 percent said that support for expansion of funding would make them less likely to vote for a given candidate. A survey of AARP members in Oklahoma revealed that about half (53 percent) of respondents would be more likely to vote for a candidate who supported maintaining or expanding the delivery of home and community-based health and long-term care services, even if it means raising state taxes.³⁵ Only 10 percent said they would be less likely to vote for such a candidate.

Changing Long-Term Care: A Growing Awareness

The need for long-term care can be a life-changing event for everyone involved. How many of us know of a Frank or a Jean? How many of us have heard of someone in Zoë’s situation? And yet the silence is almost

deafening. Frank, Jean, and Zoë, as well as Frank's son and daughter-in-law, Zoë's parents, and Jean's husband and children are nearly invisible. But their lives, and the lives of about another 30 million Americans have forever been changed by the need for long-term care.

The risk, at most points in our lives, is relatively low; but the consequences in both financial and non-financial terms, are variable but usually devastating. Yet pooling the risks of long-term care has not been a part of the political discourse. If some say they would rather die or be in a hospital bed than in a nursing home, and if others cannot speak to their children about their future health care needs, how can the public discourse on long-term care proceed?

Fortunately, about 67 percent of survey respondents do think it is likely that they will develop a chronic medical condition.³⁶ Two-thirds (67 percent) agreed with the statement "long-term care poses the greatest threat to their standard of living during retirement."³⁷ And among people age 45 and older, 60 percent said they were familiar with long-term care; although less than a quarter (21 percent) said they were very familiar.³⁸

Awareness is growing in younger populations as well. In a survey of people with a living parent age 65 or older, many revealed that they were worried about their own old age. Almost three-quarters (73 percent) reported being concerned about their ability to care for themselves without being a burden on their families. And nearly as many (72 percent) were concerned about their ability to pay for their own medical and other basic living expenses.³⁹ A survey of registered voters in Michigan aged 45 or older revealed that 55 percent of respondents thought that the state should make affordable long term care options a "top" or "high" priority.⁴⁰

These survey findings suggests that at least half the population is aware and perhaps ready for a public discussion about the policy options for confronting long-term care. What is clear is that awareness of the issues is not sufficient. Awareness raises the question of what to do but unfortunately the options for pooling risk are limited.⁴¹

Life care communities, which pool the risk among community residents, require both a substantial upfront fee and the necessity of moving into the community. Most of these communities require being above a specific age, such as 60, before you move in and that you move-in in good health. Long-term care insurance policies pool some of the risk, but such insurance is not available to everyone and does not make sense for anyone who cannot finance the gaps in the insurance coverage. The

amount of risk pooled through long-term care insurance is dependent on the individual making those choices decades before the risk is prevalent.

Awareness about the risks of long-term care is certainly necessary, but until public policies better enable everyone to pool the risk in a meaningful way, being aware will not be sufficient for families to effectively organize, arrange, and provide needed care.

Notes

1. National Center on Birth Defects and Developmental Disabilities, Center for Disease Control, Birth Defects: Frequently Asked Questions, December 12, 2006. (www.cdc.gov/ncbddd/bd/). Note that this and all references to the internet were valid as of June 1, 2007.
2. National Institute of Child Health and Human Development, National Institutes of Health, Rett Syndrome (06-5589), June 15, 2005. (http://www.nichd.nih.gov/publications/pubs/upload/rett_syndrome_2006.pdf).
3. National Safety Council, Report on Injuries in America, 2007 edition. (http://www.nsc.org/lrs/Data_Summary.doc). Calculation based on NSC data and 2005 U.S. Census Bureau national population estimate.
4. Ibid.
5. National Stroke Association, Kids and Stroke. (<http://www.stroke.org>). The incidence of stroke in children is 3/100,000.
6. American Cancer Society, 2007 Facts and Figures, 2007. (<http://www.cancer.org/downloads/STT/CAFF2007PWSecured.pdf>).
7. Mayo Clinic Staff, Multiple Sclerosis, December 6, 2006. (<http://www.mayoclinic.com/health/multiple-sclerosis/DS00188>).
8. National Parkinson Foundation, About Parkinson Disease. (www.parkinson.org).
9. Alzheimer's Association, About Alzheimer's Disease. (http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp).
10. Facts about diabetes obtained from the Diabetes Public Health Resource at the Centers for Disease Control, (www.cdc.gov/diabetes).
11. Childhood Obesity: A lifelong threat to health, Center on an Aging Society Data Profile Number 2, March 2002.
12. Who Needs Long-Term Care, Georgetown University Financing long-Term Care Project, May 2003.
13. Author's calculations using data from MEPS, NHIS, and data from Lisa Alexcxih, Nursing Home Use by "Oldest Old" Sharply Declines, (The Lewin Group, November 21, 2006).
14. From www.ppecc.org.
15. See www.ppecc.org (viewed 6.13.06).
16. The stories of Jean, Frank, and Zoë are made up. Any similarities to real people, however, are not quite coincidental since their stories have been drawn from articles about real people with these conditions. For example, see Lynne Corner, Assessing quality of life from the perspective of people with dementia and their careers, in a study prepared for the Alzheimer's Society and distributed by the Centre for Health Services Research and Institute for Ageing and Health, University of Newcastle Upon Tyne, (Taylor & Francis Health Sciences, August 2003); Katrin Bostrom and Gerd Ahlstrom, "Living with a chronic deteriorating disease: the trajectory with muscular dystrophy over ten years," *Disability and Rehabilitation*, (Vol. 26, 1388-1398, 2004); Kathryn Yorkston, Kurt Johnson, Estelle Klasner, Dagmar Amtmann, Carrie Kuehn, and Brian Dudgeon, "Getting the work done: a qualitative study of individuals with multiple sclerosis," *Disability and Rehabilitation*, (Vol. 25, No. 8, 369-379, 2003); Kathy Charmaz, "Loss of self: a fundamental form of suffering in the chronically ill," *Sociology of Health and Illness*, (Vol. 5, No. 2, 1983).

17. Summary Findings from Long-Term Care Focus Groups, April 26-June 6, 2001, Final Topline Report, Prepared for Centers for Medicare and Medicaid Services, by Barents Group of KPMB Consulting, Inc., McLean, VA, October 5, 2001.
18. Long-Term Care Insurance: Consumer Perceptions, LIMRA International and HIAA, 2002.
19. Peter D. Hart Research Associates and American Viewpoint, Long-Term Care: The Public's View National Academy of Social Insurance Survey, 2004. Hereafter referred to as the NASI 2004 Survey. Available as National Academy of Social Insurance Health and Income Security Brief No. 8 ~ November 2005 (www.nasi.org/publications2763/publications_show.htm?doc_id=317975&name=Long%2DTerm%20Care&requesttimeout=500).
20. The Costs of Long-Term Care: Public Perceptions Versus Reality, AARP, December 2001.
21. From Met Life Survey, see www.metlife.com/Applications/Corporate/WPS/CDA/PageGenerator/0,4132,P250%25E5866,00.html for the press release.
22. The Public's Views on Long-Term Care, Kaiser Family Foundation, May/June 2005.
23. The Costs of Long-Term Care: Public Perceptions Versus Reality, AARP, December 2001. Similar results had been found in the Baby-Boomer IQ Test, American Health Care Association, February 4, 1999.
24. For a review of the complexity of policies see Bonnie Burns, Comparing Long-Term Care Insurance Policies: Bewildering Choices for Consumers, Issue Paper #2006-13 (Washington, DC: AARP Public Policy Institute, 2006). To better understand the importance of the insurance agent in helping consumers make an informed choice among policies see Choosing a Long-Term Care Insurance Policy: Understanding and Improving the Process, by Robert B. Friedland and Stephanie Lewis, October 2004, and available at www.aging-society.org.
25. The National Council on Aging/John Hancock Mutual Life Insurance Company Long Term Care Survey, February 1999.
26. Ibid.
27. Baby Boomers Approach Age 60: From the Age of Aquarius To the Age of Responsibility, Pew Research Center. December 8, 2005.
28. Robert L Kane and Rosalie A. Kane, What Older People Want From Long-Term Care, And How They Can Get It, Health Affairs, Vol. 20, No. 6 (114-127).
29. Ibid.
30. Op. Cite.
31. Iowa Home and Community-Based Long-Term Care: An AARP Survey, AARP. January 2002.
32. Funding Health and Long-Term Care: A Survey on Increasing Iowa's Cigarette Tax, AARP. February 2003.
33. Long-Term Care in Michigan: A Survey of Voters Age 45+, AARP. June 2005.
34. Ibid.
35. Oklahoma Long-Term Care: A Survey of AARP Members, AARP. January 2005.
36. Harris Interactive Inc., Survey of the General Public, Adults with Chronic Conditions and Caregivers, for The Robert Wood Johnson Foundation, Johns Hopkins University, Partnership for Solutions, 2000.
37. The 1999 National Council on Aging/John Hancock Mutual Life Insurance Company Long Term Care survey.
38. The Costs of Long-Term Care: Public Perceptions Versus Reality, RoperASW for AARP, December 2001.
39. National Survey on Health Care and Other Elder Care Issues, Toplines, Family Circle and the Henry J. Kaiser Family Foundation, September 2000.
40. Long-Term Care in Michigan: A Survey of Voters Age 45+, AARP. June 2005.
41. See for example, Sheila P. Burke, Judith Feder, and Paul N. Van de Water (eds.), Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future (Washington, DC: National Academy of Social Insurance, 2005); David Blumenthal, Marilyn Moon, Mark Warshawsky, and Cristina Boccuti (eds.), Long-Term Care and Medicare Policy: Can We Improve the Continuity of Care?, (Washington, DC: National Academy of Social Insurance, 2003); Robyn I. Stone, Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century (New York, NY: Milbank Memorial Fund, August 2000) (www.milbank.org/reports/0008stone/).

About the Project

The *Georgetown University Long-Term Care Financing Project* pursues analysis designed to stimulate public policy discussion about current long-term care financing and ways to improve it. The project is supported by a grant from the Robert Wood Johnson Foundation. Additional publications are available at <http://ltc.georgetown.edu>.



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