

## Mom Has Me; I Won't Have a Me: The Impact of Caregiving on the Retirement Security of Immigrant Family Caregivers

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There is a picture in our family photo album that captures a special moment in the history of our immigrant family. My mother is looking straight at the camera, with me to her left and my younger brother to her right. Years ago when we children were assigned school projects about our families, Mom told us that was the photo used in our passport to immigrate from Taiwan to the United States to join our father who had come to America a few years earlier to pursue a graduate degree.

Mom's happy smile in that photo reflected her joy at being able not only to reunite with her husband after a long separation but also to pursue her own American Dream. She had already spent her teenage years as a refugee student escaping Communism. America in her mind – as in the mind of so many across the globe, then and now – would be a land of freedom and opportunity.

Fast forward all these decades and Mom is now the widowed matriarch of a three-generation family. She has had a chronic, degenerative disease (Parkinson's Disease) for more than 30 years and was recently diagnosed with dementia. I am her family caregiver – the term used for anyone caring for a parent, spouse, partner and/or friend. In order to care for Mom, I have had to make tough decisions that have a tremendous impact on my current financial situation as well as on my future retirement security, and that's on top of the strains and stresses of caregiving on my physical health and emotional well-being. I am among the 45 percent of family caregivers in America who have had at least one financial impact on our lives as a result of providing care for a loved one. Additionally, as a consequence of being from an immigrant family, there are unique differences in my lived experience as a family caregiver than in the experience of a non-immigrant family caregiver in this country.

### My Caregiving Journey: A Marathon, Not a Sprint

My family-caregiving experience began years ago as a long-distance caregiver first: I would use my vacation days from work to travel back to the town where we grew up to check on my aging parents. Then, with the unexpected death of our father more than ten years ago, I needed to assume full responsibility for Mom's care.

There are an estimated 53 million adult family caregivers in the United State like me who are providing unpaid care for an adult loved one or a child with special needs. As of 2019, the total economic value of the care provided by unpaid family caregivers was estimated at approximately \$470 billion – yes, that's billion with a "b". With the "Silver Tsunami" – the aging of the 78 million Baby Boomers (those born between 1946 and 1964) – in future there likely will be an increase beyond the current estimate that nearly one in five Americans (19 percent) is a family caregiver for an adult with health or functional needs.

Because of the fragmented long-term care "system" in the United States, the responsibility of caregiving typically falls upon family members. This is especially the case in Asian-American families regarding the care of a parent or

parent-in-law. Notice I did not use the word “burden” of caregiving. I recall a lecture I once attended where a Latina professor emphasized that in her culture caregiving is not a burden but an act of love. Though from a culture different from hers, I could relate deeply to what this bilingual, bicultural professor said.

## The Impact of Heritage Cultural Norms and Values

Sociologists would describe me as a 1.5-generation immigrant – someone who was not born in the United States but who arrived here early in life, as a child or adolescent. I have grown up recognizing that I have a foot each in the Western and the Eastern culture. And being of Chinese heritage, I understand that the responsibility of caring for one’s parents is a tradition that dates back millennia. I believe observing the Confucian value of filial piety (孝) is just innate in my DNA. Even though I have not read the teachings of Confucius, I accept the expectation that children will be good to and take care of their parents.

After Dad’s death, I did not place Mom in any eldercare facility. I chose to bring her to live with me in a home setting, a decision that is more common among Asian-American caregivers. I recognize that this is not an option for everyone. But all these years later, as the COVID-19 virus has led to a devastating number of deaths in congregate housing for the elderly, I am at peace with that decision I made years ago.

By receiving care in a home setting, Mom is able to enjoy the Chinese food she has always cooked and eaten. In my research into options for eldercare congregate housing, I did not find any facilities in my local community that could serve Mom the traditional food that she is used to. There has been some innovation in areas of the United States where more Chinese Americans and Asian Americans reside; for example, in the Bay Area in California, community leaders noted the need for what are called “culturally sensitive” social and health services and then created eldercare facilities that provide familiar foods and hire bilingual staff.

In caring for Mom at home, I needed to hire a paid caregiver to help me because, like many immigrant families, ours is a nuclear family. The extended family of most immigrants might be thousands of miles away, so I do not have what I call “extra hands on deck” whom I can call upon to offer support or to give me a respite break. And although the paid caregiver I hired to help me for eight hours a day does not speak Mandarin Chinese, Mom does speak enough English so communication between them has not been a problem. But other family caregivers have shared their lessons learned and have alerted me to the fact that as her dementia advances, Mom may revert to speaking only her native language. Again, care in a home setting provides a culturally competent solution because I, who have worked hard to learn my heritage Chinese language, am able to understand what Mom says and can convey her needs to others.

## The Consequences of Immigration

The 1.5-generation immigrant children like myself and the American-born 2.0-generation children of immigrants face other unique circumstances in our current family caregiving journey. These are a direct consequence of the decision of our parents to immigrate to the United States decades ago. Their generation benefited from the change to the American immigration process with the signing into law of the Immigration and Nationality Act of 1965 by then-President Lyndon B. Johnson. With the passage of time, these young men and women who came to America with little or no money in their pockets but with dreams and ambition have aged and are now “seniors”.

In all the intervening years, these early immigrants labored to survive, and hopefully one day thrive, in America. But after paying for their rent or mortgage, insurance premiums, kids’ eyeglasses, orthodontic braces, music lessons,

etc., etc., most of these parents did not have money left to buy long-term care insurance, if they were even aware of this option. Now in their old age, many of them are too well off to qualify for long-term care support under Medicaid, but too poor to afford the high entry fees and/or other expenses of assisted living, nursing homes or memory-care facilities. They have made it into the American middle class, which, unfortunately, is very much on its own and must fend for itself when faced with caregiving expenses and responsibilities, regardless of being native-born or immigrant.

I recognize that as a result of immigrating to America and leaving their homelands and families, many of the current generation of immigrant elders therefore did not experience first-hand the aging and dying process of previous older generations. They often have had no lived experiences as, nor role models of, family caregivers. As they themselves reached middle age and their own parents back home were getting on in years, so many immigrants became what are called trans-national family caregivers. They might have provided care across oceans and time zones by sending money back home, but perhaps were able to visit family only after years of saving for the trip. There are too many stories among immigrant elders of not having been able to go home to bury a loved one, of feeling guilt that the care of elderly parents fell heavily on siblings who did not emigrate or of working extra jobs in order to send money back to relatives while raising their own family in America. And it is only in recent years that communication technologies have made it possible to connect easily and cheaply with family overseas.

As immigrant communities have grown and matured, subsequent waves of immigrants have benefitted from lessons learned and shared by earlier immigrants as well as from having more in-language information and bilingual providers of services. Outside the popular Asian supermarket chain stores, the flourishing ethnic media make available free print copies of in-language newspapers. There are pages and pages of ads placed by bilingual sales representatives reaching out to immigrant communities on behalf of established insurance companies, financial advisors and law firms. Today, there is less of a linguistic barrier thanks to in-language resources when it comes to estate planning, preparing in advance for long-term care and ensuring that necessary legal documents are completed.

## You Can Lead a Horse to Water, But You Can't Make It Drink

However, having materials available in an Asian language does not mean that our elders will automatically agree to getting the necessary plans in place nor the legal documents signed related to financial planning and/or end-of-life preparations. Caregivers in Asian-American families often face difficulties in starting a conversation because death and dying are taboo topics in many families; cultural beliefs and practices create barriers to advance planning.

On the other hand, my generation of immigrant family caregivers, which might have to provide years of care because of the increased longevity of our parents, is more likely to proactively plan for our own future aging as well as for our possible physical and cognitive decline. Many family caregivers, native-born and of immigrant background, are saying, "We do not want to put our children through what we have experienced as family caregivers." And individuals like me who will age solo (with no children or life partner) and will not have a daughter or son to provide care are keenly aware of the critical need to plan strategically for what lies ahead in our lives. This presents opportunities for collaboration with financial advisors, lawyers and other professionals to map out a more informed retirement scenario as well as to make end-of-life arrangements in advance.

My father passed away suddenly and I assumed care for my mother without much time to plan. While there is no "typical" family caregiver, there are some common characteristics among all family caregivers, immigrant and native-born, that are also relevant for my own situation. All of us need support and help in our struggle to balance

multiple responsibilities: caregiving, work, running a household as well as our own too-often-neglected health and well-being:

Financial and Legal Issues for Our Loved One's Care:

- We family caregivers need help with financial information to calculate if full-time care for our elderly loved one is affordable, and if so, how should we plan for it.
- We could use guidance on how to take care of our elderly loved one's finances.
- We need help to better understand our elderly loved one's eligibility for Medicare/Medicaid and any other benefits and services.
- We need help and guidance on legal issues from elder law professionals.

Our Own Employment Issues:

- If we are still in the work force, we could use help in understanding family-leave options that would help us to juggle work and caregiving responsibilities.
- Could employers offer more flexibility (e.g., teleworking, flexible work hours, phased retirement, etc.), which would help family caregivers succeed in remaining in the workforce?

Our Own Retirement Issues:

- If we are contemplating the need to scale back our work hours or leave the work force in order to care for our elderly loved one(s), we need help in understanding the impact such a consequential decision would have on our finances and retirement: the impact on our Social Security benefits; our pension, if our workplace still offers one; our defined contribution plans; our individual retirement accounts; our investments, our savings, etc., etc.

## I Will Not Have a "Me" in My Old Age

Family caregivers, both native-born and immigrant like myself, have absorbed critical lessons from our own experiences in this rewarding but challenging role. The lunar new year began on February 12, 2021. It is The Year of the Ox according to the Chinese zodiac. The ox is a hardworking animal. It is the perfect symbol for this year during which I must work hard to do two things:

1. Reflect on what can be learned – both the challenges and the opportunities – from how diverse communities are providing care and support to loved ones in their advanced age. Can there be better support for family caregivers, a role that is critical to the emotional, physical and fiscal well-being of so many immigrant and non-immigrant families without undermining the retirement security of the caregivers?
2. Acknowledge that my own financial situation and retirement security took a hit from being a dutiful Chinese daughter caregiver and reach out to financial, legal and other professional advisors to strategically plan for my future.

I will not have a me – a dutiful daughter caregiver – as my family caregiver in my old age.

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