

## **FAMILY CAREGIVING IN AMERICA: VALUING THE INVALUABLE: FACTS AT A GLANCE**

By Michele Hendrix

As our population ages, a growing number of American adults will serve as caregivers for loved ones who are young, disabled, frail, or suffering from a chronic condition. In fact, this rapidly increasing number of family caregivers has become an essential component of the nation's health care system, providing more services in the home – free of charge – than the federal government provides in all settings combined. Caregiving is one of the most stressful jobs in America, and for many, it is not their only job. The number of adults taking care of family members or friends increases daily, and the majority of these caregivers are not providing care for compensation.

- There are an estimated **65.7** million caregivers or approximately **29%** of the U.S. adult population who are providing care to someone who is ill, disabled or aged.
- Another **52** million caregivers provide care to adults (aged **18+**) with a disability or illness.
- Some **43.5** million of adult family caregivers are caring for someone 50+ years of age and **14.9** million care for someone who has Alzheimer's disease or other dementia.
- A growing number of family caregivers care for a special needs child (**14%**) with an estimated **16.8** million caring for special needs children *under 18* years old.
- Approximately **55%** of these caregivers are caring for their own children.

The imprint on my heart is in the form of my own mother, diagnosed with dementia last year (2013), who moved into a Memory Care home this summer. My aunt who suffered a terrible stroke as a result of complications from heart disease, paralyzed and imprisoned in her body, unable to speak for 6½ years before she went to meet her maker. My Dad, living in VA hospice care for three years with multiple forms of cancer before he passed. Now, my Uncle is struggling with heart disease, early memory loss, and the recent death of his only child – my cousin. It's a difficult and delicate imprint on my life and in my heart, and it is incomprehensible sometimes. I see their faces and many more whom I have served and provided care for in the people I meet who have these diseases.

Caregivers don't only care for people with Alzheimer's disease and other dementias. There are caregivers for people with cancer, diabetes, heart disease, Parkinson's, ALS, MS, lung disease, those who have had a stroke, and many, many other health complications. Some may be caring for someone with a chronic illness or developmental or physical disability. Others might be taking care of someone who is simply having trouble maintaining independence due to the normal course of aging. Being a caregiver can be very rewarding, but it also leaves you frequently exposed to stressors like family dynamics, a disruption in the household, financial worry and changes in routines and health conditions. It is no wonder caregivers are prone to burnout. Caregiver stress is emotionally, physically, financially, and spiritually straining on the caregiving. So many caregivers often feel isolated, frustrated and exhausted by their caregiving duties. That is why family support is a key driver in remaining in one's home and in the community, but it comes at substantial costs to the caregivers themselves, to their families, church, community, and society. Caring for a chronically ill child, adult, aging parent, or family member is simply part of life, and it's something that should be

prepared for. Family members often undertake caregiving willingly, and many find it a source of deep satisfaction and meaning. There is no doubt that caregiving in today's economic climate and fragmented system of health care has a significant impact on the family members who provide care. Without question the church should be a part of this whole ministry and educational process.

### **Why Does Family Care Matter?**

The U.S. economy could explain why family members are becoming more responsible for care. With fewer or depleted savings, many people are less able to hire professional help. Historically, everyday caring for ill family members was undertaken as an expected role by women within the privacy of the extended family and in a given community. As a consequence, it was largely ignored and rarely viewed as a public issue. Such family care was typically short term, because most people did not survive to old age; they died from acute, rather than the chronic conditions of today, until the advent of antibiotics in the twentieth century. The average lifespan in **1900** was just **47** years. In **2013** the average U.S. life expectancy is **78** years, and by **2020** will be nearly **80+** years.

Today, families remain the most important source of support to older adults. Many individuals who provide assistance and support to a loved one with chronic illness or disability do not identify themselves as "caregivers" but rather describe what they do in terms of their relationship with the other person: as a husband, wife, partner, daughter, daughter-in-law, son, grandparent, grandson or granddaughter, niece, or close friend. Today an estimated **83%** of Americans say they would feel very obligated to provide assistance to their parent in a time of need. Those who take on this unpaid role risk the stress, physical strain, competing demands, and the financial hardship of caregiving, and thus are vulnerable themselves. Family caregiving is now viewed as an important public health concern.

### **Caregiving Facts and Figures**

**17%** of American workers are caregivers, or about **one in six**. Gallup's analysis indicates that **20%** of all female and **16%** of all male workers in the U.S. are caregivers. And at least **13%** of full-time workers in every major socio-economic and demographic group are caregivers; this includes **17%** of whites, **21%** of blacks, and **20%** of Hispanics.

Today more health care is happening at home. With medical advances more people are living longer and more lives are being saved. Their lives are being extended, but they're also being sent home medically fragile. It's caregivers who are the first line of defense.

Unpaid family caregivers will likely continue to be the largest source of long-term care services in the US. A new study has found that **4 in 10** U.S. adults are now caring for a sick or elderly family member as more and more people develop chronic illnesses and the population ages. As a chronic illness progresses, family members often step in to help out. There's a better understanding of the progression of the disease than that of the practitioner because the family members live with it day to day.

The estimated percentage of informal caregivers who are women ranges from **69% - 75%**. Many men also provide care, however, *female caregivers* may spend as much as **50%** more time providing care than male caregivers and are less likely to be employed full time.

Here are some surprising statistics:

- Percentage of women caregivers who report experiencing emotional stress due to their caregiving role: **40%**
- Percentage of male caregivers who do: **26%**
- Young caregivers: Nationwide, approximately **1.3 to 1.4 million**
- Of the informal caregivers who are between the ages of **8 and 18**, an estimated **70%** of young caregivers are caring for a parent or grandparent.
- Percentage of caregivers who care for family members: **83%**
- Number of informal caregivers who are the primary caregiver of the person they care for: **71%**
- Number of caregivers who report they are the *only* person providing unpaid care to the person they care for: **37%**
- Women and men, age 18 and older, who provide unpaid care to an adult age 18 or older: **44.4 million**
- Percentage of caregivers who either work or have worked while providing care: **59%**
- Percentage of employed caregivers who say they've had to make some adjustments to their work life, from reporting late to work to giving up work entirely: **62%**

Researchers found that the number of caregivers increased **10%** between **2010** and **2013**, they surveyed **3,014** adults nationwide and found that *most caregivers* were between **30** and **64** years old. Caregivers most frequently reported unmet needs: finding time for myself (**35%**), managing emotional and physical stress (**29%**), and balancing work and family responsibilities (**29%**).

Another change we are seeing in the US is that of grandparents serving as caregivers to their grandchildren. As "Grammy" to 11 grandchildren I find these statistics very informative and very revealing.

#### **Grandparents as Caregivers:**

- **7 million:** The number of grandparents whose grandchildren under the age of 18 were living with them in 2011.
- **2.7 million:** The **number of grandparents** responsible for the basic needs of one or more grandchildren under the age 18 living with them in 2011. Of these caregivers, **1.7 million were grandmothers** and **1.0 million were grandfathers.**
- **1.9 million:** The number of **married (including separated) grandparents** responsible for caring for their grandchildren.
- **1.7 million:** The **number of grandparents** in the **labor force** responsible for their own grandchildren under the age of 18. Among them, **338,000 were 60 years or older.**
- **5.5 million:** The number of children under 18 living with a grandparent householder in 2011. Nearly half, **48%** or **2.6 million**, were *under age 6*.
- **10%:** The percentage of children in the U.S. living with a grandparent in 2012, totaling 7.1 million.
- **2.7 million:** The number of children living with both their grandmother and grandfather in 2012.

With the information provided in this article try to imagine these unfathomable numbers blending together into incomprehensible mounds of challenges, choices and change, suffering and strain. What it reveals to me is one caregiver, one that represents the hundreds I've known and served over the years. This person is tired, overwhelmed, distraught, scared, challenged, and doesn't know where to turn for help. They feel incredibly alone. Yet they are not alone. As we've learned, they literally are in the company of millions. It's a bittersweet reality. Caregiving touches almost every family and in very different ways – different health conditions; different situations; even different cultures. Family caregivers provide a complex array of support tasks that extend across physical, psychological, spiritual, and emotional domains. In fact, family caregivers form the foundation of the health care system in the United States. Understanding the family caregiver and what they need to be successful is where the church has the opportunity to help provide, presence, prayer, resources, support and care for its members as they meet and navigate these escalating needs, challenges, and changes.

#### REFERENCES:

1. U.S. Census Bureau; CDC National Center Health Statistics; Institute for Women's Policy Research; [National Alliance for Caregiving](#); [Family Caregiver Alliance](#).
2. U.S. Census Bureau, 2011 American Community Survey.
3. *Caregiving in the United States*; National Alliance for Caregiving in collaboration with AARP; November 2009.
4. Schumacher KL, Stewart BJ, Archbold PG, et al.: Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncol Nurs Forum* 35 (1): 49-56, 2008.
5. Alecxih LMB, Zeruld S, Olearczyk B: Characteristics of Caregivers Based on the Survey of Income and Program Participation. National Family Caregiver Support Program: Selected Issue Briefs. Washington, DC: U.S. Department of Health and Human Services, Administration on Aging, 2001.
6. Source: America's Families and Living Arrangements: 2012.
7. Administration on Aging (2004). *National Family Caregiver Support Program (FCSP) Complete Resource Guide*. Washington, DC: Author. Butts, D. M. (2005). *Kinship Care: Supporting Those Who Raise our Children*. Baltimore, MD: Annie E. Casey Foundation.
8. Seniorhelpers.com/caregiver-facts

**Ms. Michele Hendrix** has served two terms as the President of POAMN. She has worked for over 25 years to advocate, educate, involve, and motivate people in the process of aging and self-care; and to recognize the connections among church, health care, non-profit, community, state, federal, and local agencies while encouraging adults of all ages in managing their self-care, chronic conditions, respite, and caregiving roles. Michele has focused her work on intergenerational and interfaith programs for adults, evidence-based health promotion, ministry programming and development, respite for caregivers, and fall-prevention programs. She is a Deacon, Stephen Leader, Caregiver Specialist, Speaker and Trainer with expertise in Older Adult Ministry, Intergenerational Ministry, and Caregiving for all ages.