

## Caregiving in the US, 2015

A study by the National Alliance for Caregiving and AARP

The National Alliance for Caregiving (NAC) and American Association of Retired People (AARP) recently released a comprehensive study on non-paid caregiving in the US. The full study is titled Caregiving in the US, 2015 and is available online at: <http://www.caregiving.org>

This study looked closely at family and other unpaid caregivers in the U.S. The goal of the study was to examine the following areas:

- The prevalence of caregivers in the United States
- Demographic characteristics of caregivers and care recipients
- The caregiver's situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
- How caregiving affects caregiver stress, strain, and health
- Information needs related to caregiving
- Public policy and caregiver support



In addition, there were some unique areas of exploration including:

- Medical/nursing tasks
- Hospitalization of care recipients
- Supports provided to and impacts on working caregivers
- Older caregivers, ages 65-plus

The full report is 80+ pages, but the Key Findings section provides an excellent overview and is only a few pages long. I would recommend it to social workers and other's involved in supporting families providing. There were a few things in the findings that had resonance with my experience with homecare. But first, below I've summarized a few basic stats from the report:

- Approximately 34.2 million Americans (about 10% of the US population) provided unpaid care to an adult age 50 or older in the prior 12 months.
- Sixty percent (60%) of these caregivers are women, 40% are men.
- Most (85%) are caring for a relative, with about half (49%) caring for a parent or parent-in-law.
- On average, unpaid caregivers are providing 24.4 hours of care per week, but nearly a quarter of caregivers provide more than 41 hours per week.
- In addition to help with ADLs, caregivers also spend considerable time coordinating care among various health entities (skilled care, non-medical help, doctors, etc.)

- Fifty-seven percent (57%) of caregivers are providing “nursing tasks.” The higher-hour caregivers are more often providing this type of care.
- About 10% of caregivers are caring for their spouse, but a large majority of spousal caregivers (78%) indicated that there was no other help.
- Overall, only about one-third (32%) of unpaid caregivers caring for loved ones get any paid help from caregivers, housekeepers or others.

The biggest need gap identified in the study was that many of these caregivers find performance of these tasks difficult, with the largest percentages of those finding these tasks hard being for those caring for people with dementia or who have been providing care for more than 5 years. From the study:

“The intersection of feeling prepared to provide medical/nursing tasks with actually performing these tasks reveals some important gaps in caregiver preparation. Most commonly, caregivers are doing medical/nursing tasks without any preparation (42%). Just 14 percent of caregivers who assist with medical/nursing tasks report having received some preparation or training. More than 6 in 10 higher-hour caregivers are performing medical/nursing tasks without any prior preparation. Caregivers in the most complex care situations are the ones most likely to be performing medical/nursing tasks without any preparation—62 percent of high-burden caregivers are performing medical/nursing tasks without prior preparation.”

(Source: Caregiving in the US, 2015, page 9, [www.caregiving.org/wp-content/uploads/2015/05/2015\\_CaregivingintheUS\\_Final-Report-June-4\\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf))

The other major findings, which are somewhat related to this gap, included perceptions about whether or not the caregiver has choice about providing the care and the associated stress and strain associated with caregiving. Not surprisingly, those who feel they have no choice in providing care, and those who feel unprepared to provide care experience greater levels of stress and/or greater incidents of poor health.

Of these findings, there were a couple of items that seemed very true to my experience as an agency providing care to folks in their homes.

First, family members bringing their loved one home from the hospital or rehab often lack instruction, skills and confidence in providing the care needed. This is especially true for children caring for their parents for the first time. They are often very intimidated to help with things like bathing and toileting, and often have false expectations about the amount of help they will get from a visiting nurse. One of the key things our aids provide to families dealing with care for the first time is basic training and support until others in the household providing care really gain confidence with care tasks and builds trust with the patient. For families that perhaps cannot afford ongoing help, just getting help that first week or so can make a real difference in getting the patient and family transitioned to care at home. Trained aides can help establish routines, provide an extra pair of hands during those first stressful days, ensure that follow up services and appointments are happening in a timely manner, and can introduce and reinforce safe practices at home.

Second, I have encountered many times when children play a minor role in care because an elderly spouse is taking point with care. The study shows that these “couple” relationships are much more likely not to have any outside help, and I often encounter a much stronger dynamic of resistance to getting help. These couples are holding fiercely onto their independence. Interestingly, the report showed that in general, spousal caregivers do not suffer any more or less stress and strain than the general caregiver population. However, common sense dictates that the more elderly the couple/caregiver, the greater likelihood of physical injury to themselves or their care recipient. I have observed this now several times in home settings where the “88 year old husband” is caring for the “86 year old wife,” whose care has moved physically beyond his abilities. These couples often hide their needs, living day-by-day in denial that help is warranted until there is a crisis of some kind – usually a fall or injury – often to the “healthy” partner. Only at this crisis point are children summoned and then realize how difficult and dangerous the situation has progressed. I often counsel folks that getting even modest amounts of care early in the process of aging (even just a few hours a week) helps facilitate better practices at home and helps families be more open to adding help as the client’s needs change over time. This is especially true for those caring for spouses with dementia. I have several clients where we provide help just one day a week so the caregiver can have some respite and free time. It goes a long way in keeping these couples together longer, and makes the transition to more help when needed easier.

Given demographic trends and associated changes to health care laws and insurance, more and more care is being pushed to family caregivers. There is a tendency only to call in outside help when things have progressed to an unbearable point. There is great efficacy in getting even modest amounts of outside help sooner rather than later – for both the patient and the caregiver. Lack of outside support results in resentment, isolation, and greater stress and strain for both the caregiver and patient. Whether some extra help is needed for a short-term transition or a long-term care situation, helping families – especially spouses – accept the help of other family, neighbors or a paid service can make a big difference in their lives.



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