

Spotlight

Breaking Stereotypes: Spotlight on Male Family Caregivers

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In the United States, family caregivers are the backbone for the delivery of supportive services for individuals with a chronic, disabling, or serious health condition. They identify, arrange, and coordinate services and supports; provide emotional support; accompany their family member or friend to health provider visits; administer medications; assist with personal care (such as bathing and dressing); pay bills and deal with health insurance; and perform other vital activities to help individuals remain in their homes and communities for as long as possible. In light of the aging of the population, increases in life expectancy, and shrinking families, the supply of family caregivers is unlikely to keep pace with future demand.¹

Although the “typical” family caregiver is a 49-year-old woman who takes care of a relative, caregivers on the whole are becoming as diverse as the American population.² Men, a group traditionally not recognized for performing caregiving tasks, are rising to the challenge. These husbands, brothers, sons, sons-in-law, partners, friends, and neighbors are joining, either by choice or necessity, the army of family caregivers providing care across the country. However, there is a paucity of research that has exclusively examined the impact of caregiving within and among diverse male family caregivers.³

40 percent of family caregivers of adults are men—which equates to 16 million male family caregivers in the United States.

Prior studies were predominately qualitative in nature and several had methodological challenges, including small sample sizes that limited the generalizability of the findings.

Using data from the *Caregiving in the U.S. 2015* survey,⁴ this Spotlight highlights male family caregivers, providing current information about the experiences and challenges facing them today.

Who Are Male Family Caregivers?

According to the *Caregiving in the U.S. 2015* survey, 40 percent of family caregivers of adults are men,⁵ which equates to 16 million male family caregivers in the United States. Although the average age for a male family caregiver is 47.8 years old, there is



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great variation by age and the relationship between the caregiver and the care recipient. For example, 28 percent of all male family caregivers are millennials, and the average age for this group is 26.9 years old. The average age for a son caring for a parent or in-law is 46.4 years old, while that of a male family caregiver caring for a spouse/partner is 62.5 years old.

Male family caregivers are a diverse group in many respects. Other notable caregiver demographic information includes the following:

- Roughly 59 percent of all male family caregivers are White, 13 percent are Black, and 7 percent are Asian American Pacific Islander. Although 19 percent of all male family caregivers are Hispanic, nearly one-third of millennials (32 percent) reported being Hispanic.
- Nearly half of all male family caregivers (48 percent) have a high school diploma or a diploma plus some college education, compared with only 37 percent with a college or graduate degree.
- More than 4 in 10 (44 percent) of all male family caregivers have household incomes of under \$50,000 a year.
- Over half (56 percent) of male caregivers are married and slightly more than a quarter (26 percent) are single, never married. About 11 percent of male family caregivers identified themselves as being gay, bisexual, or transgender.

Also telling is caregivers' feelings about how they took on their role. Similar to females, nearly half (49 percent) of all male family caregivers felt they had no choice in taking on this responsibility. Notably, about 6 in 10 male family caregivers caring for a spouse/partner indicated they had no choice. This is not surprising. Studies indicate that husbands play a significant role caring for a spouse or partner, provide more hours of care, and are more likely to be primary caregivers with little to no support from other unpaid family members compared with other male family caregivers.^{6,7} More than half (52 percent) of all current male family caregivers expect to be caring for someone in the next five years. Nearly two-

thirds of male family caregivers (64 percent) expect they will be caring for an aging parent or in-law.

It's All about Relationships: The Caregiver to Care Recipient Experience

Evidence suggests that men caring for an aging parent or spouse will sacrifice and do whatever is necessary to provide care and ensure that the needs of their loved one are met.^{8,9} For example, over half of male caregivers (63 percent) reported that they were the primary caregiver. Male family caregivers were mostly providing care to an aging parent or in-law (49 percent) or a spouse (13 percent) with a long-term physical condition that required assistance with activities of daily living (ADLs) such as eating, dressing, or bathing, or instrumental activities of daily living (IADLs) such as managing finances and meal preparation. Although more than half of all male family caregivers (53 percent) had help from other unpaid caregivers in caring for the care recipient, more than three-fourths (78 percent) of male family caregivers caring for a spouse did not.

Other factors that affect the male caregiver experience involve age, living situation, and the recipient's condition:

- Although the average age of the care recipient is 68.8 years old, sons caring for a parent or in-law were slightly older at 74.8 years of age.
- The care recipient is likely to live in the caregiver's household or within 20 minutes of his or her home. More than a quarter of care recipients (26 percent) lived alone.
- About 23 percent of care recipients had Alzheimer's or experienced mental confusion.
- One-third of Hispanic male family caregivers and 30 percent of Black male family caregivers indicated that they were providing care to someone with emotional or mental health problems.

On average, male family caregivers had been providing care for 3.9 years at the time of the survey. However, there were differences between males caring for a spouse and those caring for a parent. For example, male family caregivers caring for a spouse or partner had been providing care for a longer period of time. They provided care for about 5.1 years.

Sons caring for a parent or in-law provided care for 4.1 years, and millennials provided care for 2.7 years on average. Such figures underscore the long-term commitment made by male family caregivers, even in the case of millennials, who are often juggling school, work, and caregiving without paid help.

Rising to the Occasion: Male Family Caregivers Are Performing a Range of Caregiving Tasks

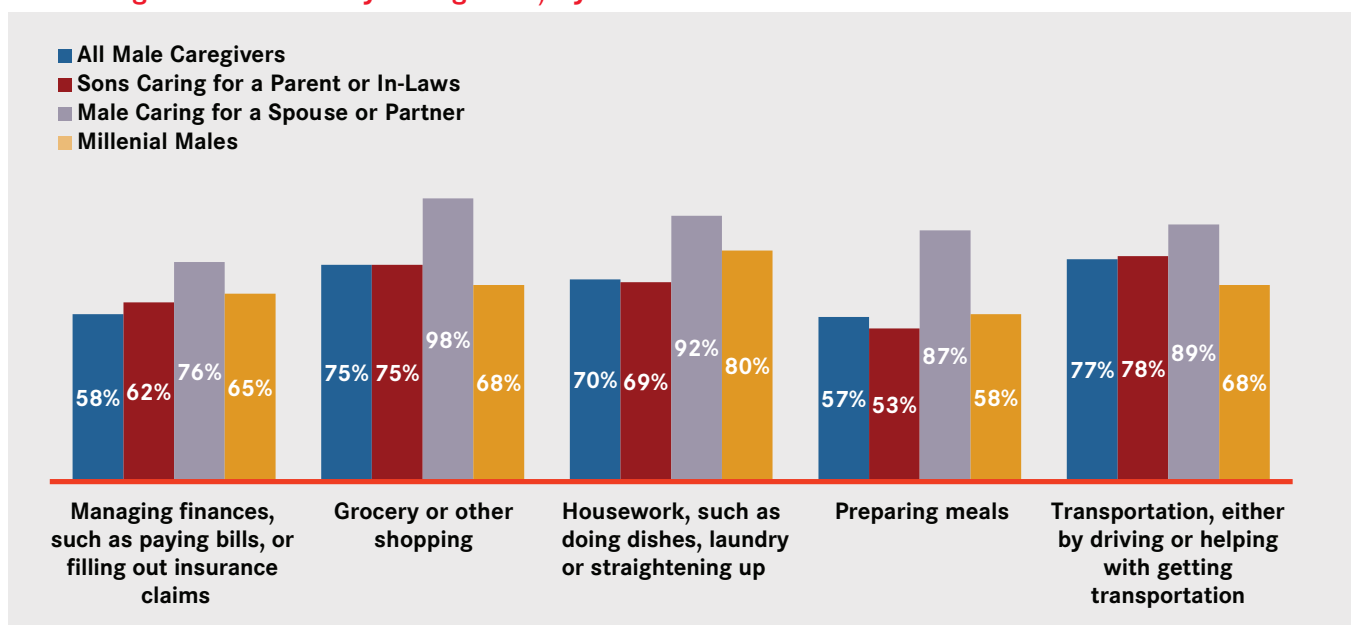
Although there are some misperceptions that male family caregivers perform activities related only to managing finances and providing transportation, evidence suggests they are also performing a range of personal care activities that include helping their loved ones with eating, dressing, bathing, and toileting.¹⁰ For example, more than 4 in 10 (44 percent) male family caregivers reported helping the care recipient get in and out of beds and chairs; more than one-quarter (29 percent) said they helped the care recipient get dressed; 30 percent reported helping the care recipient get to and from the toilet; and about 1 in 4 (24 percent) reported helping the care recipient with eating, bathing, and showering. Male family caregivers helped with 1.7 ADLs on average, but male caregivers caring for a spouse reported helping with 2.1 ADLs.

Male family caregivers perform such personal care tasks despite having some reservations about doing so, or experiencing some discomfort and difficulty with the task. The transition of having to bathe or dress an aging parent or grandparent can be difficult for any family caregiver. However, this is especially challenging for male family caregivers, in part because they have less background in having to perform these activities.¹¹ In fact, over half (54 percent) of male family caregivers in the *Caregiving in the U.S. 2015* survey found it moderately to very difficult to help recipients with their personal, intimate care needs.

The survey revealed that in addition to helping care recipients with personal care, male family caregivers were also helping their loved ones with a range of other activities such as driving, shopping, home maintenance, and managing financial matters, just to name a few (see figure 1). Male family caregivers, on average, helped with 4.2 IADLs. However, male caregivers caring for a spouse assisted with 5.2 IADLs.

Compared with male caregivers for an aging parent, male caregivers for a spouse were more likely to be managing finances (76 percent), shopping for groceries or other necessities (98 percent), doing housework (92 percent), preparing meals (87 percent), and helping with transportation (89 percent). Male

FIGURE 1
Percentage of Male Family Caregivers, by IADL Tasks



family caregivers were also more likely than female family caregivers (37 percent and 27 percent, respectively) to arrange for outside services, such as nurses, home care aides, or meals on wheels. Sons caring for an aging parent or in-law were more likely to arrange for outside services compared with male family caregivers caring for a spouse.

Despite some misperceptions, male family caregivers are performing medical and nursing tasks as well as a range of personal care activities.

Medical and Nursing Tasks

According to the groundbreaking 2012 report *Home Alone*, family caregivers often perform complex medical and nursing tasks, such as injections, tube feedings, wound care and treating pressure ulcers, administering parenteral medications and intravenous fluids, and operating medical equipment. This report also found family caregivers were seldom adequately prepared by clinicians to take on these challenging tasks.¹² It's not surprising, therefore, that in addition to performing ADLs and IADLs, male family caregivers are increasingly performing tasks that nurses traditionally have performed. The following are indicative of that trend:

- More than half (54 percent) of male family caregivers experienced at least one hospitalization of their care recipient in the past year. A quarter of male caregivers reported that their spouse had three or more hospitalizations.
- More than half (56 percent) of all male family caregivers were performing medical and nursing tasks, and three-fourths (75 percent) of male caregivers caring for a spouse were performing these medical and nursing tasks.
- About 47 percent of male family caregivers who performed these tasks were giving medicine, pills, or injections.

- About 72 percent of all male family caregivers who performed medical and nursing tasks indicated that no one prepared them to do so.

According to the survey, male family caregivers preferred several different approaches for learning how to perform medical and nursing tasks:

- More than half (58 percent) indicated that they would like a qualified person to show them how to do medical and nursing tasks.
- About half (49 percent) indicated that they would like hands-on training where they would perform the medical and nursing task while a qualified person watched.
- One-third indicated that they would like instructions with pictures of what to do.

Thus, although preferred learning approaches vary, respondents shared a common theme: the desire for more concrete training. Presumably, any such training would be preferable to none. In response to the *Home Alone* report, which reaffirmed the findings in this Spotlight, AARP created a model state-level bill called the CARE (Caregiver, Advise, Record, and Enable) Act to support the millions of family caregivers in America who are performing complex medical/nursing tasks with very little to no training on how to care for their loved ones safely at home. Currently, 33 states and the District of Columbia passed the law, which

1. calls for the hospital to record the name of the family caregivers at the time of admission of the loved one;
2. provides family caregivers with adequate notice prior to hospital discharge; and
3. provides a simple instruction of the medical tasks they will be performing when their loved one returns home.

This is one major example of legislation moving across the country to help family caregivers who are having to navigate the health care system and support their loved one as they transition from the hospital setting back home.

More than one-third (37 percent) of male family caregivers did not inform their employers about their caregiving responsibilities; the percentage of male family caregivers who did not inform their supervisors was even higher for millennials (45 percent).

Balancing Caregiving Responsibilities and Work Demands

Caregiving, of course, can be hard by itself. Balancing caregiving duties, work, and other responsibilities can be a major challenge for all family caregivers that adds to the difficulty. Overall, the majority of adults caring for an aging parent or spouse have worked at a paying job at some point during their caregiving experience. However, the study found that male family caregivers were more likely (66 percent) to be working compared with female caregivers (55 percent). The large majority of employed male caregivers were working 40 or more hours per week at the time of caregiving.

Regardless of gender, caregiving responsibilities often require family caregivers to make workplace accommodations. The study found that nearly two-thirds (62 percent) of male family caregivers had to make changes in the workplace as a result of their caregiving responsibilities (see figure 2). Moreover, their caregiving duties affected their work in other significant ways:

- Nearly half (48 percent) of male family caregivers went in late, left early, or took time off to provide care.
- About 15 percent of male family caregivers took a leave of absence or went from working full time to part time to provide care.

- Less than 10 percent of male family caregivers turned down a promotion (8 percent), received a warning about their performance or attendance (7 percent), or retired early or gave up working entirely (6 percent).

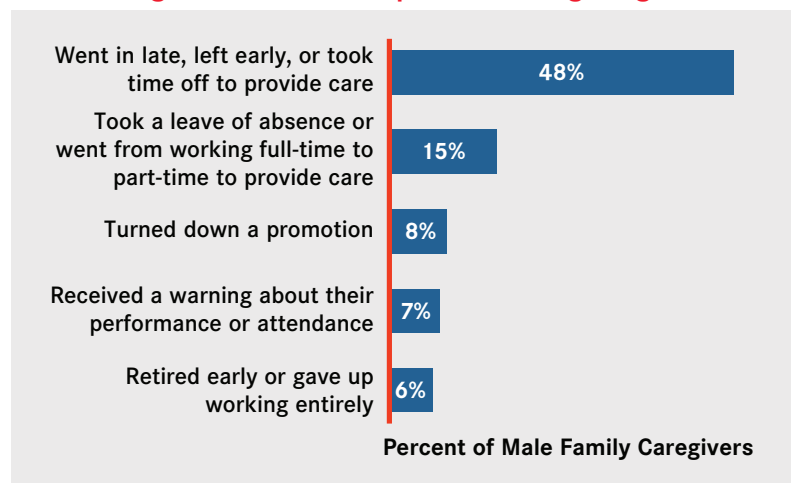
Qualitative studies indicated that younger men had more “difficulties” in the caregiving role and communicated particular “psychological stress” when having to choose between work responsibilities and caregiving responsibilities.¹³ More than one-third (37 percent) of male family caregivers did not inform their employers about their caregiving responsibilities. The percentage of male family caregivers who did not inform their supervisors was even higher for millennials (45 percent).

The Strains of Caregiving

Although caregiving can be rewarding and positive, many family caregivers experience significant physical, psychological, and financial stressors in association with their caregiving role:

- Nearly two-thirds (62 percent) of male family caregivers indicated that their caregiving experience was moderately to very stressful.
- Almost half (46 percent) of male family caregivers experienced moderate to severe physical strain due to caregiving responsibilities.

FIGURE 2
Male Caregivers and the Impact of Caregiving on Work



- More than 4 in 10 (44 percent) male family caregivers reported moderate to high financial strain as a result of caregiving.

Caregiving's Evolving Landscape

Caregiving is not easy for any caregiver, men included. A range of social demographic factors, including the aging of the population and shrinking family size, is influencing the pool of family caregivers both now and into the foreseeable future. Male family caregivers, an understudied population, are stepping up to the plate in record numbers. What may come as a surprise to some is the diversity of

experience even among male family caregivers. As the findings from the *Caregiving in the U.S. 2015* survey illustrate, male family caregivers are not just managing finances or helping with housework; they are also performing medical/nursing tasks and helping with personal care activities such as feeding, dressing, and toileting. Many of these experiences vary by the relationship to the care recipient, intensity of caregiving tasks, and length of time caregiving. One thing that is clear, however, is that understanding these diverse experiences, challenges, and needs is important for developing tools and resources that will meet male family caregivers where they are.

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