



ISSN Print: 2394-7500
ISSN Online: 2394-5869
Impact Factor: 5.2
IJAR 2018; 4(10): 380-383
www.allresearchjournal.com
Received: 02-09-2018
Accepted: 28-09-2018

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Impact of caregivers in home management

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Abstract

This article examines the diverse and evolving roles of caregivers of older adults and the impact of assuming these roles on caregiver health and well-being. It describes the tasks of the carer, the dynamic nature of care over time, the increasing complexity and scope of the carer's responsibilities and the issues involved in making substitution decisions. Family caregiving is more intensive, complex, and long-term than in the past, and caregivers rarely receive adequate training for their role. A compelling body of evidence suggests that many caregivers experience negative psychological effects. Some caregivers are at higher risk than others, especially those who spend long hours caring for older adults with advanced dementia. Caregivers should have access to high-quality, evidence-based interventions aimed at reducing or preventing adverse health effects.

Keywords: Caregiving, family, older adults, management

Introduction

As a society, we have always depended on families to provide emotional support and assistance to their elderly parents, grandparents and other family members when they can no longer function independently. This article explores the diverse and evolving roles of family caregivers of older adults and the impact of assuming these roles on the health and well-being of caregivers. It describes the trajectory and dynamic nature of caregiving over time, the increasing complexity and scope of caregiver responsibilities, including issues related to the role of family caregivers as surrogate decision-makers, and evidence of the impact of caregiving on the health and well-being of caregivers of older adults.

Caregiver Trajectory

Despite many common experiences, the roles of caregivers are highly variable during caregiving. The diversity of families, the timing of entry into the care-giving role, the duration of the role in relation to the overall life course of the caregiver, and the transitions in care experienced over time all shape the nature of the care-giving role.

The committee conceptualized care over time as a 'caring trajectory' to emphasize the dynamic nature of the role and the different directions it can take. The care trajectory includes transitions in both the care needs of the older adult and the environment where care is provided.

In populations where care recipients become increasingly impaired over time, such as increasing frailty, dementia, Parkinson's disease, or advanced cancer, the role of caregiver expands accordingly. In populations in which care recipients experience short-term or episodic periods of disability, such as early-stage cancer and heart failure.

Caring for older adults occurs in all settings in which care is provided and often involves interaction with multiple providers, transitions from hospital to home or rehabilitation facility, moving to a senior residence or assisted living facility, placement in nursing care, home and finally end-of-life care. These transitions and role changes, along with the care recipient's health and functional status over time, affect the caregiver's social, physical, and emotional health (Carpentier *et al.*, 2010; Cavaye, 2008; Gibbons *et al.*, 2014; Peacock *et al.*, 2014) [2, 3, 5, 8]

Individuals do not provide care in isolation from other roles and responsibilities in their lives. Their personal lives—as spouse or partner, parent, employee, business owner, community member—intertwine with caregiving in different ways at different times. In ideal circumstances, a carer can balance the responsibilities and rewards of competing roles, such

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as childcare or paid work, with their caring responsibilities. However, the accumulating care demands and costs of long-term services and support (LTSS) can overwhelm and undermine other dimensions of a person's life. Additional complexity in trajectories occurs when family members disagree about the type of care needed and how it should be provided (Dilworth- Anderson *et al.*, 2002) [4], or when family roles and responsibilities change over time.

Stages in the care trajectory

Although the care-giving role is highly variable over time, different stages in the care-giving trajectory can be distinguished when the role is considered longitudinally. For example, care may follow a trajectory reflecting increasing care-giving responsibilities punctuated by episodic events such as hospitalizations and placements in rehabilitation or long-term care facilities. Figure 3-1 shows how care for people with dementia typically follows a relatively linear trajectory driven by the progressive cognitive and functional decline of the care recipient. The trajectory begins with the caregiver realizing there is a problem. Over time this develops into increasing care needs as the care recipient requires help with household tasks and then with self-care tasks. End-of-life care may include placement in a long-term care facility or enrollment in a hospice program. Note that the tasks required of a caregiver accumulate over time. Each phase of the trajectory brings with it new challenges for the caregiver to face. This stage includes recognition and increasing awareness within the older adult's social network of disabilities, changes in health, and/or behavioral change that signal the need for some level of caregiving. The older adult may downplay the need for care during this phase

because of their concerns about becoming a burden to others (Cahill *et al.*, 2009) [1]. Awareness of a functional disability may come gradually, as in someone with slowly progressive dementia, or suddenly, as in someone who has had a stroke or traumatic brain injury.

Increasing care demands

Schulz and Tompkins (2010) illustrate the care-giving trajectory for a typical older individual with functional decline who lives in the community and who over time experiences increasing reliance on the caregiver for assistance. Initial tasks may include monitoring clinical signs and medications, as well as managing homework, communicating with health professionals, and providing emotional support to the care recipient. Over time, care-giving tasks often expand to include providing self-care tasks, obtaining substitute decision making authority for care recipients, and providing specialized medical care such as administering injections.

Roles of family caregivers

Assisting with Household Tasks, Self-Care, Mobility, and Supervision

Nearly all caregivers help older adults in need of care with household tasks such as shopping, laundry, housework, meals, transportation, bills, money management, and home maintenance (NAC and AARP Public Policy Institute, 2015) [7]. As indicated in Figure -1, these responsibilities are often daily ones if the older adult needs help because of health or functional limitations: 44 percent of caregivers reported helping with chores every day or most days.

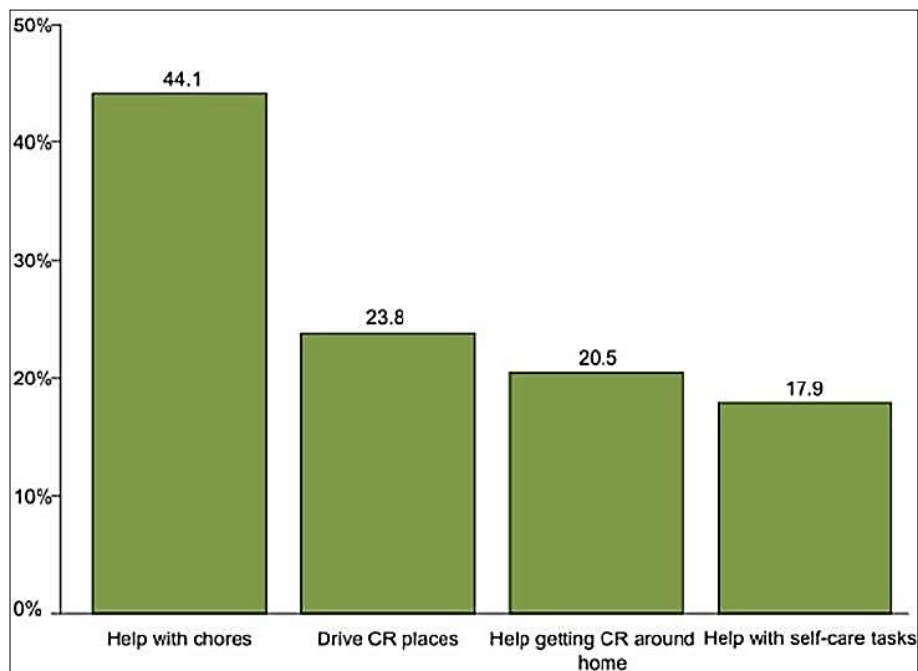


Fig 1: Percentage of caregivers who helped every day or most days during the past month, by type of help, 2011

Notes: Includes family caregivers of Medicare beneficiaries age 65 and older in the continental United States who resided in community or residential care settings (other than nursing homes) and received help with self-care, mobility, or household activities for health or functioning reasons. CR = care recipient.

Self-care and mobility tasks include walking, transferring (eg, getting in and out of bed and chairs, transferring from bed to wheelchair), bathing or showering, grooming, dressing, feeding, and toileting (eg, maintaining continence, managing incontinence). Helping with self-care is a frequent and sometimes daily role of some caregivers; 17.9 percent

of caregivers reported helping with self-care every day or most days.

Providing Emotional and Social Support

When older adults first need caregiving because of increasing frailty or onset of a debilitating disease, they need emotional and social support that are different from the usual exchanges among family members. One important change is in the balance of reciprocity in the caregiver-care recipient relationship. With increasing needs, the care recipient may be able to give less to the relationship while needing more from it, despite efforts to maintain some reciprocity (Pearline *et al.*, 1990) ^[9].

In addition, the care recipient's own emotional response to their changing circumstances may require a higher level of emotional support from the caregiver. Caregivers may find themselves dealing with unknown depressive symptoms, anxiety, irritability or anger in the care recipient. These changes can be so subtle that they are almost imperceptible at first. With advancing frailty, changes in the relationship may only be recognized in retrospect after they have been underway for some time.

Conversely, changes in a relationship can occur suddenly, like a stroke. For example, among stroke caregivers, issues in the caregiver-stroke patient relationship (including poor communication, role reversal frustration, and intimacy issues) are most stressful.

Decision Making and Surrogacy

In 2010, at my parents' request, I received both general and healthcare powers of attorney. The healthcare power of attorney contains both a living will and a HIPAA [Health Insurance Portability and Accountability Act] authorization and gives me broad authority to get health information and make decisions. (I always carry them with me on a USB memory stick.) (Kenyon, 2015) ^[6].

Carers are often involved in decision-making with care recipients and, in some circumstances, for care recipients. However, the nature of caregiver involvement varies. Types of decision-making roles include directive; participatory; supportive or guiding; advisory; defense; and tries to hold back and let the older adult decide. Care recipients with cognitive impairment may require substitute decision making, as discussed below, although individuals with mild to moderate cognitive impairment often can express preferences and make decisions.

Risk factors for adverse outcomes

The above review clearly shows that a significant proportion of caregivers experience a wide range of adverse outcomes, including impairment of psychological and physical health, disruption of social relationships, and potential mistreatment of the care giver or recipient. However, these negative effects are not universal. While nearly half of caregivers experience emotional stress associated with care giving, a much smaller proportion experience adverse effects on physical health.

All the variables listed in Figure-2 have been identified in one or more studies as risk factors for adverse caregiver outcomes. These risk factors fall into six categories:

1. Demographics factors
2. Intensity and type of care-giving tasks
3. Caregivers' perceptions of care recipients' suffering
4. Caregivers' own health and functioning.

5. Caregivers' social and professional supports
6. Care recipients' physical home environment

Conclusion

This article concerns our dependence on family caregivers to take on increasingly complex and demanding roles. As a society, we have always depended on families to provide emotional support and help their older members with homework and personal care. In today's health care and social service systems, providers expect family caregivers—with little or no training—to manage complex technical procedures and equipment at home for seriously ill care recipients. Some family caregivers express fear of making a life-threatening mistake.

Caregiving demands appear to take a toll on family members on the front line of supporting older adults. Substantial evidence suggests that family caregivers of older adults are at risk compared to Non caregivers; they have higher rates of depressive symptoms, anxiety, stress and emotional difficulties. Evidence also suggests that caregivers have lower self-rated physical health, elevated levels of stress hormones, higher rates of chronic disease, and impaired health behaviors.

The effects of care are not all negative. Numerous surveys suggest that for some, caregiving instills confidence, provides lessons in dealing with difficult situations, brings them closer to the care recipient, and reassures them that the care recipient is well cared for. The caregiving experience and its impact is highly individual and depends on a wide range of personal and family circumstances, such as the caregiver's own health, the level of disability of the care recipient, financial resources, and the competing demands of work and family. Gender, the relationship between caregiver and care recipient, family dynamics, proximity to the care recipient, race and ethnicity, culture, personal values, and beliefs all play a role.

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