

## Special Article – Family Caregivers

# Supporting Patients and Peers Who are Family Caregivers

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## Abstract

The concept of *family caregiving* has finally risen to prominence in both popular culture and professional literature. The National Alliance for Caregiving and AARP recently released an annual report highlighting the prevalence of caregiving. With family caregivers representing more than 40 million Americans, this translates to 1 in 8 adults caring for another adult or older adult (65 and older). The Centers for Disease Control (CDC) recognizes *family caregiving* as a public health priority of national concern. So what does this mean for healthcare professionals, including physicians and nurses? Because many patients are family caregivers for an older relative, healthcare professionals should be inquiring about their caregiving role and its impact, both positive and negative, on their overall well-being. Further, healthcare professionals need to recognize that the support afforded to family caregivers should also be extended to peers and colleagues who are providing care to their patients and then return home to provide elder care to a family member. These caregivers are known as double duty caregivers. Essentially, this means they are never “off duty” between family and professional care duties. We argue that healthcare professionals, authors included, have room to do better in supporting the needs of patients and peers who are engaged in elder care and this process starts with simply identifying caregivers and offering them a link to community resources.

**Keywords:** Family caregiving; Healthcare professionals; Elder care; Double duty caregiving; Employee assistance program

## Introduction

It seems to have been a long time coming, but the concept of *family caregiving* has finally risen to prominence in both popular culture and professional literature. The National Alliance for Caregiving and AARP [1] recently released an annual report highlighting the prevalence of caregiving. With family caregivers representing more than 40 million Americans, this translates to 1 in 8 adults caring for another adult or older adult (65 and older). The Centers for Disease Control (CDC) recognizes *family caregiving* as a public health priority of national concern [2]. Our Former First Lady Rosalynn Carter summed up this phenomenon when stating “There are only four kinds of people in this world: those who are caregivers, those who will be caregivers, those who will need caregivers, and those who have been caregivers.” We are all touched by family caregiving. As healthcare professionals, it is crucial for us to learn and communicate about caregiving issues and advocate with and for caregivers and care receivers.

## Identifying Caregivers

One simple way we can serve as advocates is by inquiring if the patients and clients that we serve are engaged in family care. In some of the caregiving programs offered to help caregivers better advocate for them, curriculum prompts caregivers to discuss their caregiving status with their health care team: “Have you told your doctor you are a caregiver?” Caregivers in these programs often respond, “No, I haven’t been asked.” or “No, it never really occurred to me to talk to my physician about my caregiving.” We argue that if healthcare providers

are expected to document a number of other demographic and health characteristics about their patient (e.g., marital status, employment, education, substance use, behavioral health status), then knowing about caregiving status is equally valuable to fully appreciating the patient’s experiences and needs. Why is this information so critical to capture? Because the caregiving role can have a significant impact, in positive and negative ways, on a caregiver’s well-being. Because the caregiving role can impact the caregiver’s social support network and family relationships. Because the caregiving role has the potential to improve the well-being of both the care receiver and the caregiver. Berg-Weger and her colleagues [3] among others have documented those caregivers who embrace their caregiving role and report more positive feelings about their experience in turn provide higher quality care for a longer period of time.

## The Role of Caregiving

It has been shown that interventions can be important and useful to assist caregivers in mastering the role of caregiving [4]. Caregiving mastery has been identified as an important aspect in reducing the harmful impact of role overload and role captivity on mental health outcomes such as anxiety and depression [5]. Adjusting to and mastering the role of caregiver varies based on individual experiences, characteristics and relationship styles. It is important to acknowledge that caregivers typically navigate a period of role acquisition and adjustment that can be traced in behavioral (i.e., role mastery), subjective (i.e., role satisfaction) and interpersonal (i.e., relational conflict) indicators of health. Many people report positive experiences in their role as a caregiver, including a sense of giving

back to someone who has cared for them, opportunities for personal growth, increased meaning and purpose in one's life and setting an example for younger generations [6]. These experiences have been referred to as *positive aspects of caregiving* (PAC), to recognize the value in studying caregivers who report satisfaction with their role, not only because they are more likely to provide better care, but because it moves us beyond the discussion of caregiving as simply burdensome or distressing [7].

Clearly, we cannot overlook or dismiss the very real challenges reported by family caregivers. These may include challenges associated with competing family demands, paying for the care, taking time away from work, or missing one's own medical appointments. Thus we return to the aim of helping healthcare providers become more aware of their patients who are engaged in elder care.

## Caring for the Caregiver

According to the CDC, caregivers provide the backbone of our health system [2]. Our formal healthcare and long-term care systems are not currently designed to handle the care needs of many of our older adults. We all depend on family caregivers to augment our healthcare system especially now that the median hospital stay is shrinking (5.2 days for persons 65 and older according to a 2012 report) for persons 65 and older [8]. Older patients may be sent home still in need of fairly complex medical care that is generally provided by family caregivers. The great majority of elder care is provided in the home without facility-based support or staff, as a result of older adults electing to age in place. Caregivers deserve better support and training so that they can manage both the complex care that is oftentimes required and the daily care that can appear routine but requires skills, patience, and stamina. If caregivers are not able to manage their own healthcare needs, for example, they may sacrifice their own doctors' appointments to make sure their loved one gets to the doctor, or they do not eat well or exercise routinely, or they isolate themselves when their loved one's needs grow more challenging or embarrassing, then we are left with two patients. These patients are the original care receiver plus now the caregiver who will likely need care him or herself without informal and formal supports to augment the care they provide.

## Discussing the Caregiver Role

Perhaps family caregivers do not discuss their caregiving role with their own physician due to time constraints, perceived lack of importance, or uncertainty if disclosing this role will actually result in improved care or access to resources. Perhaps physicians or other healthcare providers do not raise the issue because they are unaware of community resources or simply lack the time to address the needs to their appropriate level [9]. This situation presents an opportunity to make both healthcare providers and family caregivers aware of resources, including the Alzheimer's Association, state and local area agencies on aging, adult day services and adult protective services, respite agencies, long-term care communities, palliative care, and hospice.

## Double Duty Caregivers

If physicians and other healthcare providers are encouraged to become more sensitive to the needs of their patients who are family caregivers, what about healthcare professionals themselves who are

family caregivers? These individuals have been referred to as *double duty caregivers*, because even when "off duty" from their job as a nurse or aide, they remain "on duty" caring for family members, particularly older family members. Essentially, this means they are never "off duty" between family and professional care needs. According to nurse researcher Catherine Ward-Griffin and her colleagues [10], the constant negotiation between professional and personal care responsibilities leads to compassion fatigue and poor physical and emotional health. Double duty caregivers who don't receive support are more at risk for adverse personal and professional outcomes, including harmful consequences like making medication errors.

But why are healthcare providers becoming default family caregivers? There are several theories as to why this may be occurring, including that these individuals are already in a helping profession and perhaps can tap their professional skills to support family care. The conversation might sound something like this, "Your sister is a nurse, she's trained to take care of people so she can do this for your father, as well." In Virginia alone, where the co-authors teach and conduct research, there are an estimated 270,000 healthcare workers who are also family caregivers [11].

## Demands of Double Duty Caregiving

The demands of double duty caregiving can result in a strain on the healthcare system. Rates of absenteeism or presenteeism (present on the job but not 100% engaged) are at risk of increase. It is estimated that nearly 20% of health care system clinicians are double duty caregivers. Nurses are a case in point. Nurses make up the largest professional group of healthcare staff in the United States [12]. The demand for nurses is expected to reach a point where there could be a shortage of up to 1.2 million nurses by 2020 [13]. This shortage is the result both of a growing and aging population, and challenges with nursing turnover [14]. The economic costs of registered nurse turnover are estimated at anywhere from \$21,000-\$31,000 per nurse [15]. The true costs, when considering patient safety, patient satisfaction and staff morale, are incalculable. Therefore, it is very much in the interest of healthcare leaders to be attentive to the needs of the nursing workforce who are double duty caregivers. Nurses are but one example, however, as staff in any role in the healthcare system may find themselves in a double duty caregiving role.

## Caregiver Resources

What resources are available to support staff in the healthcare system? What should healthcare systems be doing to support their double duty caregivers? Are Employee Assistance Program benefits being utilized? Are these Employee Assistance Programs equipped to meet the needs of double duty caregivers? What is the role of supervisors and managers? How can they personally connect with their employees and demonstrate a caring response? There is an absence of evidence that might direct healthcare systems and their staff, and thus, this is an area ripe for the design and implementation of evidence-based programs tailored to the needs of these caregivers who are peers in healthcare. After all, recognizing all caregivers, families and peers, as part of the care team validates their critical role and enhances their well-being and that of those receiving their care. We have room to do better.

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