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EDITORIAL

Identifying family caregivers as preventive medicine: An essential component of comprehensive primary care

Geri Lynn Baumblatt[1] and Allison J. Applebaum[2]

1. Difference Collaborative Alliance, Chicago, IL, USA
2. Department of Psychiatry and Behavioral Sciences Memorial Sloan Kettering Cancer Center, New York, NY, USA

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Corresponding Author:
Geri Lynn Baumblatt
Difference Collaborative Alliance, NFP
Chicago, IL, USA
gerilynn@mac.com

SUMMARY

Many patients are also family caregivers, who care for an ill or disabled family member or friend. Most do not "self-identify" as caregivers. Over time, caregiving can have significant effects on caregivers, as they often put their own health last. Primary care is an ideal place to identify caregivers through screening for caregiving status as part of patient history. This practice allows for the triaging of caregivers to appropriate supports and services, and as such is a form of preventive medicine.

Key Words
Family caregiver; care partner; carer; primary care; preventive medicine

INTRODUCTION

The COVID-19 pandemic cast a spotlight on the enormous number of family caregivers, carers, or "care partners," who care for (or help care for) an ill, disabled, or injured family member or friend. Many *patients* are also caregivers who help with everything from managing medication and transportation, navigating health care and insurance, and assisting with personal duties such as bathing and groceries. Increasingly, caregivers assume responsibilities once performed by medical professionals, usually without any formal training. They help people recover from procedures and manage conditions like cancer, dementia, and Parkinson's disease. In the United States, a 2020 pre-pandemic report from the America Association of Retired Persons (AARP) and the National Association for Caregiving found that 53 million Americans were already family caregivers.[1] The number today is likely much higher.

Caregiving is often a marathon. On average, it goes on for 4.5 years, with 29 per cent serving as caregivers for more than 5 years, and 14 per cent for 10 years or more. On average, caregivers spend 24.4 hours a week providing care; a quarter provide 41 or more hours; 60 per cent also work;[1] and many are caregivers multiple times throughout their lives.[2] While a large number of parents have not returned to work due to childcare, four times as many family caregivers have been unable to return to work.[3] Importantly, time off from the workforce to care for a loved one can often last much longer than expected, creating new stressors as people lose their income and health benefits, and many take on new debt.[4]

Family Caregivers' Health Is at Risk

While often rewarding, caregiving is physically, emotionally, socially, financially, and existentially challenging. Caregivers are at risk for their own medical and mental health problems, and 23 per cent say caregiving has made their own health worse.[2] Approximately half of caregivers report clinically significant symptoms of depression and anxiety,[5] and many experience post-traumatic stress disorder or related symptoms.[6] Medical complications such as sleep difficulties and fatigue[7] and cardiovascular disease[8] are common and can impair caregivers' capacity to carry out their responsibilities.

Caregivers often put their own health last; their doctors' visits, healthy meals, and exercise often fall by the wayside, and are replaced with unhealthy coping behaviors, such as increased use of alcohol or smoking.[9] Social networks become constricted, leading to further isolation. The COVID-19 pandemic amplified all these factors—psychological distress, increased responsibilities, and isolation—and created added responsibilities and underscored the critical role caregivers play.

The Dual Challenge of Helping Caregivers Identify and Connect with Resources

Unfortunately, family caregivers often do not connect with services like support groups or respite care that could help mitigate their distress and protect them from poor psychosocial and health-related outcomes. This fact is due, in part, to the time and financial cost associated with such services, as well as the availability of support for caregivers more broadly. Another barrier to psychosocial service use, however, is that many caregivers do not self-identify as caregivers. Instead, they see themselves as partners and spouses, daughters, sons, parents, and neighbours. And because caregiving often starts with smaller tasks and intensifies over time, people often do not track its growing impact until they are in a crisis.

Some people caring for a family member or friend are also averse to the term "caregiver," not wanting the caregiving role to define them or infringe on their personal relationship with their loved one.[10] In fact, it is frequently only through interactions with their loved one's healthcare team that people first connect the dots to their caregiving identity.[11] Generally, this connection is unintentional and often occurs when caregiving is already at an intense or crisis state (eg, during a hospitalisation). This late-stage identification results in most caregivers failing to receive support or connect with resources early, when they could help prevent intense stress, burnout, job and income loss, and poor health and wellbeing.

In the US, the only routine identification of caregivers occurs via The Caregiver Advise Record and Enable Act (The CARE Act), which has now passed in 45 states and territories. At the time of admission, it requires hospitals to document the contact information for the patient's caregiver in the patient's medical record, alert caregivers when their loved one is transferred or discharged, and to train them to care for their loved ones at home.[12] But The CARE Act is limited to documentation of caregiver contact information, and often occurs late in the caregiving trajectory when patients are admitted to the hospital; it does not address caregiver wellbeing, such as thorough screening for caregiver distress, or identifying caregivers as patients with their own care needs. To implement these steps in a manner that is legally, ethically, and financially sound, a separate caregiver medical record is needed,[13] but this is not yet the standard of care.

Primary Care: An Opportunity to Identify Family Caregivers Earlier

Primary care is an ideal environment to identify caregivers early. Here, the caregiver *is* the identified patient, with their own medical record. With this foundational step in place, clinics can screen caregivers for distress and identify support for them early in their caregiving trajectories. Physicians and care teams are in a unique position to identify caregivers by adding a simple question to a patient history. It is an easy way to better understand the stressors and demands with which patients are coping, and to consider the impact caregiving likely has on their health and health-related behaviours. As such, integrating caregiving status into the health history is a form of preventative medicine.

While more robust programs and caregiver assessments are optimal, we propose primary care teams start by adding one question to histories and visits:

Do you currently provide care or help to care for an ill, disabled, or injured family member or friend?

This language avoids the terms "caregiver" and "care partner," which may be unfamiliar or may sound more formal than how patients think about their activities. This question can be integrated into the medical record or pre-visit questionnaires so that primary care teams are aware before the appointment to discuss caregiving status.

If the patient confirms they are a caregiver, the provider should ask about the type of care they provide and how it impacts their physical and mental health. While the next step of connecting people with support services is outside the scope of this editorial, the simple act of identifying caregivers and asking them, "*Has caregiving had a negative impact on your health?*" and "*What kind of support do you need with caregiving today?*" is on its own a powerful intervention. Ideally, reported concerns would trigger a validated caregiver assessment to learn more about unmet needs and identify supportive care referrals (eg, psychosocial support, nursing education, respite care).

This call to integrate screening for caregiving status into primary care is not new. Others, such as the authors of the 2005 Caregivers Count Toolkit,[14] a 2011 editorial in *American Family Physicians*,[15] and a 2022 article in *Health Affairs*[16] identified this opportunity, but it has not seen widespread adoption. Currently in the US, even when a family caregiver is identified, often there is no formal place for that data to be entered in the electronic medical record (EMR). That said, progress is being made. For example, Rush University Medical Center in Chicago created the Rush Caring for Caregivers model,[17] which includes educating healthcare staff about the importance of caregivers and The CARE Act, creating fields in the EMR to add the caregiver so that caregiver data are not buried in a progress note, and administering evidence-based caregiver needs assessments, followed by short-term therapeutic interventions to address medical task training and what matters most to both the care recipient and the caregiver.

Rush also added caregiving questions to the patient's Annual Wellness Visit, including: "*Are **you** responsible for helping a family member or friend? Does a family or friend help you?*" This program is currently being piloted at six other Age-Friendly Health Systems. To date, the Caring for Caregivers model has focused on caregivers of older adults; and data show reduced caregiver depression, anxiety, and burden, as well as reductions in inpatient admissions, lengths of stay, and emergency department visits for care recipients.[17]

The past decade of research in caregiving science has underscored the fact that otherwise healthy people often become second-order patients due to family caregiving and the years of challenges and stressors that usually accompany it. Our healthcare systems rely heavily on this often-invisible caregiver workforce for the health and success of those they care for, but concurrently, do very little to support these caregivers in their roles. As many caregivers are unaware of the ways caregiving raises their own health risks, and are unidentified with their caregiving status more broadly, primary care teams are in a unique position to address caregiver wellbeing. If primary care screens patients for caregiving status, providers have greater capacity to identify those in need of support and can connect them with resources. Ultimately, doing so will prevent caregivers from becoming casualties of the love, support, and care they provide.

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