

# Opening Remarks: The Informal Caregiving Landscape

Laura Frain, MD, MPH

We are delighted to feature a Q&A from Laura Frain, MD, MPH to kick-off this GHDonline Expert Panel, [Supporting the Informal Caregiver: Implications for an Aging Society](#). Dr. Frain is a geriatrician in the Division of Aging's Center for Older Adult Health at Brigham and Women's Hospital. In this discussion, Dr. Frain outlines the present and future informal caregiving landscape in the United States; common challenges faced by caregivers and providers; and next steps to better support these caregivers around the world. This Expert Panel will address many of the themes mentioned by Dr. Frain, and we encourage you to add your thoughts and questions to the discussion throughout the week.

## Current landscape

**GHDonline: Can you describe informal caregiving in the United States in terms of who the caregivers are, their role, and the challenges informal caregiving presents?**

Laura Frain, MD, MPH: One of the most amazing things about caregiving in this country is that it's incredibly diverse. There are caregivers, or "care partners," of every age, gender, racial and ethnic group. Appreciating this diversity across individual caregivers is vital because so often the perception and public discourse around caregiving in the United States is negative. A more nuanced public discourse surrounding caregiving, as we're doing here on GHDonline, will be really transformative, and will allow us to really appreciate caregiving more as a culture.

A 2015 joint report from AARP and the National Alliance of Caregiving, "[Caregiving in the United States](#)," paints a really great picture of the current caregiving landscape in this country. From that report, we are able to understand and highlight both the diversity of experience and the prevalence of informal caregivers in the United States. There are 43.5 million adults who provide informal care to older adults. In our current situation, you're either providing care for a loved one, you know someone who is, or this will be something that happens in your own life at some point.

Most of the informal caregiving performed in the US (85%) is for relatives, with about 50% for parents or parents-in-law, but much is also for spouses. It's critical to understand these different cohorts of caregivers. What we've seen in practice and research is that there are your typical caregivers, and there are categories that we refer to as "higher-hour caregivers," or caregivers who provide more than 20 hours of caregiving a week.

There are also older caregivers. We learned from this report that there are many caregivers who are 75 years of age or older. Each of these different groups of caregivers may have different needs, traits, and requirements associated with caring for their own health and wellbeing. This is crucial when considering the role of providers and clinicians in supporting informal caregivers—providers need to understand the unique needs of different types of caregivers.

**GHDonline: What do you think the role of the provider is in supporting informal caregivers?**

LF: Providers and clinicians need to start having open-ended discussions with caregivers and patients about how it feels to be a caregiver, and the experiences of caregiving. This allows providers to draw out the caregiver’s needs, the dynamics of their relationship with their care recipient, and to begin thinking through how to better support that particular patient and caregiver group. Opening up the discourse will allow us to really understand that we need to balance the portrayal of caregiving in the United States, and perhaps across the world, to recognize that certainly it can be stressful, overwhelming, and have negative health consequences for caregivers, but that it also has many positive and resilient features for all involved.

## Challenges

**GHDonline: What are the most pressing challenges faced by informal care providers?**

LF: Caregivers face significant minute-by-minute, hour-by-hour changes in the needs of their care recipient. They are increasingly becoming responsible for managing the health care experience of their care recipients. This is becoming more prevalent as we move care out of hospitals and try to prevent hospitalizations, which puts enormous responsibility on informal caregivers. Caregivers are becoming crucial partners in improving the quality of care, health, and well-being of our older adults, yet they are often not valued or trained in this role.

Often caregivers of older adults are managing their care recipients’ many complex chronic conditions through medication management, coordination of appointments—all the things we’re focusing on as a nation to improve the health and wellness of older adults. This is often referred to as the “invisible workforce,” yet there is little emphasis on including, valuing, educating, and supporting these caregivers. We have dialogues about increasing the formal workforce caring for older adults, or providing more nuanced geriatric training to those who already provide care, but we ignore this invisible workforce of caregivers when it comes to training and building capacity.

Caregivers are not only interfacing with the health care system, but are also helping their care recipient navigate activities of daily living (ADLs) or independent activities of daily living (IADLs) like bathing, dressing, and grocery shopping. Frequently, these caregivers that are managing the health care and ADLs/IADLs of their loved one and navigating the complex health care system have significant and severe caregiver stressors in their life such as fixed income and being older age dealing with their own health care problems. Targeting caregivers with more needs or who are higher risk is a challenge, but it's essential.

**GHDonline: As a geriatrician, what are the most pressing challenges you regularly encounter when caring for elderly patients and their informal caregivers?**

LF: The primary challenge my geriatric team and I face is not having enough time to properly determine the caregiving support, or lack thereof, for our patients. So much of our visits, care, reimbursements, and medical structure in general focus on a disease-based model. But in my work I've realized you can't be so tethered to this model. In order to support disease-based care, you have to know the support structure surrounding individual patients. The John A. Hartford Foundation [conducted a poll in 2012](#) where they asked older adults about the key questions their primary care providers addressed in their visits. The poll found that 70-80% of older adults reported their provider never asked them about the caregiving support they receive, or how they function with their ADLs. If providers aren't addressing this critical area of informal care, and don't know how their patients get through their days, then we can't even begin to understand the care support network around them that is often essential to supporting disease-based care, helping them feel healthy and well, or achieving what matters most to them.

## Resources

**GHDonline: What programs and services are in place to help informal caregivers cope with the challenges they face on a day-to-day basis? What are the barriers to accessing these resources?**

LF: One of the main areas of need caregivers often highlight is information. They want information both on understanding the needs of the person they're supporting, but also on how to best support themselves. They want information on living as a caregiver, managing their stressors, managing their care recipient's behaviors and issues like incontinence, discussions around end-of-life care and advanced care planning. There are many resources out there, such as:

- [The National Alliance for Caregiving](#)
- [Caring.com](#)
- [Lotsa Helping Hands](#)

- [The Family Caregiver Alliance](#)
- [Alzheimer's Association](#)—even for all families and caregivers of people with any type of dementia, this is a phenomenal resource
- The first step can often be a referral to the Elder Services group, an aging service access point, for particular areas in a region. From there, the family can connect with the local resources for older adults and caregivers.
- [Family Caregiver Handbook](#), which is available free online—provides support for caregivers such as training, chat rooms, and support groups that address the day-to-day stressors of caregiving.

While there are an abundance of resources available to caregivers, there are many barriers to accessing them. This is an important area to address in order to work towards reducing these barriers.

Time is a major constraining factor for caregivers who are often working full-time jobs, living their own lives, while also fulfilling their caregiving duties. The time it takes to learn and read about available resources, understand the content, potentially receive training on caregiving tasks, and go to support groups is a huge barrier to utilizing these resources for many caregivers.

I witness this often in my own work. We tried to run a caregiver educational session at Brigham & Women's Hospital, and we couldn't find one time that work for enough people. That's one of the wonderful things about technology and online access—it is giving caregivers a virtual space that works for whatever moment of time they might have.

While time is a limiting factor, there are also significant financial barriers to accessing these tools and resources. The qualifications for being eligible for caregiving services and assistance can be very strict, and often only a small percentage of people are accepted. Caregivers will get connected to services, but then they learn how expensive these services are, and are unable to participate due to financial issues.

Other barriers include inflexible work environments—often, caregivers' own jobs are not understanding when it comes to their care recipients' needs. Caregivers may need to come in and leave work early to support their loved one, but need to use vacation time due to the rigidity of workplace policies. We may recognize childcare, but frequently don't recognize elder care, and that's really hard for caregivers. There are respite services available, but again, there are financial barriers to accessing these respite caregiving opportunities.

## Looking to the future

### **GHDonline: What additional programs and services should be in place to help informal caregivers?**

LF: In health care systems, we need to develop more formal programs for including caregivers and care partners as part of the care team. We often talk about “patient activation” as one of our pillars for improving health care. As we continue to think about patient activation in that discussion, policies and programs should allow for the development of more nuanced programs for caregivers focused on health care training needs.

We need programs and services that help people do the caregiving that means so much to them, but we need to eliminate or lessen the economic and financial tolls that these services place on caregivers. Caregivers need things like paid family leave, tax and social security credits, and flexible work environments.

We often see that our most vulnerable patients, like those with dementia, have the highest out-of-pocket costs of the older adult population. We desperately need proper respite care programs for caregivers to manage themselves, their own needs, and provide respite care for the care recipient. These services should not be cost-prohibitive for most, allowing caregivers—who are often older adults in their mid-life with their own health care issues—to address their own needs. This can prevent caregivers who may otherwise neglect their own needs avoid serious consequences later in their life.

It is necessary to create paths for open discussion around caregiving so caregivers and providers can access proper tools in ways that are convenient for them. If training programs are needed, they should be available online so that they are accessible no matter the location or time, such as during their commutes. They should be able to access these programs whenever they can fit into their lives.

### **GHDonline: What can we learn from cross-cultural models of caregiving, aging, and health & wellness?**

LF: In order to think hard and move caregiving into a balanced discourse, we need to look at other cross-cultural models of what aging really is and how we feel about aging in the United States. If we don’t tackle that, we won’t be able to even start thinking about supporting caregivers. Since aging in this country has such a negative connotation, it’s going to be very important that we learn from other cross-cultural models where aging is perceived the same way and, alternatively, where caregiving is valued and holds a different sense of role and value in those communities.

In Arthur Kleinman's piece, "[The Odyssey of Becoming More Human](#)," he discusses his own experience with caregiving and emphasizes that one of the greatest challenges is keeping caregiving central to health care. If we think about that, we can examine the challenges that other parts of the world are facing and use this to inform our discussion around the benefits of intergenerational transfer of care. These are two-way relationships: a caregiver may give a lot to the care recipient, but the care recipient is also giving a lot to the caregiver. By opening the discussion up to the world, we will see the complexity of this relationship, but also the beauty of it, not just the burden and the difficult parts.

**GHDonline: What small changes can caregivers, aging adults, and providers make to ease the burden (or enhance the positives) of informal caregiving?**

LF: The first step will be to seriously open the discussion around what it feels like to be a caregiver, and what it means to those involved, along with the whole spectrum of potential benefits associated with caregiving. We talk about negative health consequences, but the data suggests there is actually a healthy effect of caregiving, and that some caregivers are living longer and have positive health benefits from caregiving.

Small changes for caregiving, and for all of us, include finding a way to be mindful around the actual experience of caregiving. This piece of understanding can truly make a difference in the individual day-to-day experience of caregivers. There are many resources around mindfulness-based practices in the setting of care provision for care recipients. Some of the most transformative experiences happen when people have been enabled to bring mindfulness practice into their caregiving tasks. It can be a deeply changing experience, both difficult and meaningful at the same time.