

Supporting the Informal Caregiver: Implications for an Aging Society

Discussion Brief by Eddy Ang, MD

BACKGROUND

Informal caregiving is defined as the “the help and support family members and friends provide daily to individuals who are either temporarily or permanently unable to function independently”.¹ Family Care Alliance defines informal caregivers as “**unpaid** individuals (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.” According to the Los Angeles County Department of Public Health, over 80% of care to the recipients in the United States is provided through informal caregiving, which translates to a staggering savings of 375 billion dollars in 2007, approximately 2.7% of the total GDP for that year.

Informal caregiving is culturally regarded as the norm in many parts of the world, yet caregiver burden is universally underrepresented. The overall health of caregivers is directly related to the health outcomes of care recipients. In many cultures, informal caregivers are not provided with any training and are expected to navigate the labyrinthine health systems without professional assistance.

Characteristics of those who are at risk for caregiver burden include “female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver”.² In addition, informal caregivers may be working full time, and have serious health conditions themselves. In many cases, it is the elderly caregivers providing care to the needy, resulting in tremendous burnout. To further exacerbate the issue, with increased life expectancy and reduced birth rate, there is a growing shortage of informal caregivers to care for their own elderly members.

On June 13, 2016, GHDonline launched a week-long virtual panelist discussion on “Supporting the Informal Caregiver: Implications for an Aging Society” (<https://www.ghdonline.org/supporting-informal-caregivers/>), which has garnered tremendous interest and enthusiasm, as evidenced in the total 115 replies from the participants around the world. The participants were noted to be both culturally and geographically diverse, and represented nearly every continent, including North America (US, Canada, Haiti), Asia (India, China, Bangladesh, Dubai, Afghanistan), and Africa (Nigeria, Zimbabwe, Rwanda, Uganda, Mozambique).

¹ http://publichealth.lacounty.gov/ha/reports/habriefs/2007/Caregiving_Final.pdf

² Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver Burden. *JAMA*. 2014;311(10):1052. doi:10.1001/jama.2014.304.

Admittedly, there is consensus that adequate training in various caregiving skills for the caregivers will improve the quality of care and overall health of care recipients. Common barriers and challenges to high-quality training that were identified in the discussion range from limited support from statutory organizations, social stigma and negative perception of informal caregivers, to a paucity of community-based support mechanisms and resources.

KEY TAKEAWAYS

The information and knowledge aggregated in the discussion threads can be categorized into **5 pillars**:

■ Health care structures

- Many underscored the importance of improving the currently fragmented health systems and allowing real-time discussions among relevant providers and specialists via technology, such as Internet of Things (IoT). Currently, there is a lack of connection between acute care hospitals and post-discharge caregivers during care transition. It's particularly challenging for caregivers to navigate the highly complex health systems and various providers.
- The labor intensity required of caregivers varies in different senior housing settings, such as independent living communities with least external assistance, assisted living where assistance with medications is available, and finally home care where caregivers are inundated with myriad challenges, such as time-consuming custodial care.
- A national integrated program, Program of All-Inclusive Care for the Elderly (PACE), has been successful in allaying caregiver burden by offering comprehensive care to those who are nursing home-eligible, yet wish to live in the community safely.³ The PACE participants receive medical care and physical therapy at the centers, in addition to various nonclinical activities to keep them socially engaged.
- Newer acute care models can also prove to be beneficial to the patients and their caregivers. For example, the Orthopedic Trauma Service and Geriatrics co-management model at Brigham and Women's Hospital ensures that elderly patients receive optimal postoperative care during hospitalization, in order to minimize the likelihood of hazardous geriatric complications, such as delirium, falls, uncontrolled pain and healthcare-associated infections. Similarly, the Division of Gerontology at Beth Israel Deaconess Medical Center also provides elderly patients with comprehensive preoperative consultations so as to maximize the potential of an uneventful recovery.
- In most primary care models in the United States, as a result of our payment system, a primary care visit typically lasts only 15 minutes, allowing severely insufficient time for the providers to address various issues, which subsequently become significant burden to the caregivers.

³ Boulton C, Wieland GD. Comprehensive Primary Care for Older Patients With Multiple Chronic Conditions. *JAMA*. 2010;304(17):1936. doi:10.1001/jama.2010.1623.

■ Financing

- There was an appreciation in the discussion for the roles of geriatricians in assisting the families and caregivers by advocating high-quality care for both the caregivers and recipients. It is also paramount that providers be attentive to caregiver stress and clues for elder mistreatment.⁴ However, there is a mismatch in the supply and demand of geriatricians primarily because of the lackluster reimbursement mechanisms.
- It's important that adequate federal funding be allocated to caregiver-related research and programs, such as the Rosalyn Carter Institute for Caregiving and NYU Caregiver Counseling and Support Intervention.⁵ Private payers should collaborate with federal programs to effectively finance the silver economy and provide cohesive care.

■ Public policy

- Currently there is a pressing need for individualized and high-quality training programs for informal caregivers, particularly those who provide end-of-life support to the terminally ill. While adequate education is universally deemed crucial for the caregivers, one of the participants raised the possibility of potential exploitation of low-cost, trained caregivers in countries without proper regulations.
- Most hospital systems around the world do not provide training for the caregivers due to lack of established regulations and protocols. Even in resource-rich countries, most caregivers, especially those of lower socioeconomic status, are not aware of the local resources available to them.
- At the Catholic University of Mozambique, Faculty of Science of Health, each medical student is required to follow at least 3 families (including elderly) from the very beginning of their medical education. This curriculum affords the opportunity and platform for the students to be better trained in providing psychosocial support to the caregivers.
- The concept of tight-knit communities was introduced in the discussion, such as peer-to-peer support groups, micro-communities where locally available resources are mobilized among 300-500 residents and neighbors, as well as the innovative landlord-tenant model which allows the forlorn elderly to offer reduced rents to the young and healthy, who provide assistance with house maintenance, transportation and grocery shopping in return.

■ Technology

- The majority of discussions revolved around the use of technology and its potential to improve care and ameliorate burden for both the care recipients and their caregivers. Specifically, the implementation of technology has to be locally acceptable and culturally sensitive in order to achieve its maximum benefit.
- Many agreed that the advent of smartphones and iPads had improved the interactions of the care recipients and their families. Notably, one of the comments highlighted the

⁴ Ritchie CS. Living With an Aging Parent. *JAMA*. 2011;306(7):746. doi:10.1001/jama.2011.1163.

⁵ http://www.rosalynncarter.org/caregiver_intervention_database/dementia/nyu_caregiver_counseling_and_support_intervention/

need for the technology giants to innovate and design simple and user-friendly devices for the baby boomers who are not necessarily tech-savvy. From a behavioral economics standpoint, technology is also conducive to improving social isolation, depression and anxiety, hence better overall health outcomes. However, it was widely considered that remote monitoring technology cannot supersede human contact. Social media, as useful as it seems, can sometimes pose dangers to the vulnerable aging population, who may fall prey to reprehensible acts of scams and phishing emails, and may be ill-equipped to handle privacy and security breach.

- Telemedicine / telehealth was another recurring theme. A variety of telemedicine models, both proprietary and free, were viewed as promising resources to upend or complement, to say the least, the current health care delivery system. For instance, there are two provider-facing telehealth programs within the Division of Gerontology at the Beth Israel Deaconess Medical Center, ECHO-AGE and ECHO-CT (Care Transition). ECHO-AGE targets the frail aging population with advanced dementia and behavior disorders, and provides free consultation and support for the primary care teams, with the goal of optimizing nonpharmacologic strategies and reducing the use of antipsychotic medications which are known to increase mortality rates. In similar vein, ECHO-CT aims to close the communication loops and maximize knowledge sharing with the care teams following hospitalizations.

■ **Accountability**

- Since informal caregivers are usually unpaid, their contributions to the society are oftentimes taken for granted. Caregivers are more likely to be women who oftentimes have to give up their jobs in order to meet the demands of caregiving. While it's easy to understand the economic impact on these caregivers at present, the long-term effects on their economic well-being are usually overlooked, such as less savings for retirement and lower social security benefits, not to mention that women need their retirement savings last longer due to longer average life expectancy.

CONCLUSION

Informal caregivers play a pivotal role in our daily lives and remain an indispensable human capital. It's critical to recognize their needs, provide adequate resources and education to empower them and alleviate their burden. Federal governments and various private stakeholders should work together towards a caregiver-friendly society.