

# Recommendations to Improve Health Outcomes Through Recognizing and Supporting Caregivers



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The need to integrate health care with “social care,” or an understanding of an individual’s social context, is well-recognized by clinicians ([https://www.nap.edu/resource/25467/09252019Social\\_Care\\_recommendations.pdf](https://www.nap.edu/resource/25467/09252019Social_Care_recommendations.pdf)). With a greater understanding of the impact of social/societal determinants of health (SDOH) on health outcomes, there is increasing focus on assessing peoples’ access to resources to meet their daily health needs. SDOH have been defined as “conditions in the social, physical, and economic environment in which people are born, live, work and age (<https://www.healthypeople.gov/2010/hp2020/advisory/SocietalDeterminantsHealth.htm>).” These conditions include housing, work conditions, food access, and financial resources. The National Academies of Science, Engineering, and Medicine; World Health Organization; and United States Department of Health and Human Services all recommend assessing individuals’ social situations, identifying needs, and meeting those needs through providing appropriate healthcare and community resources ([https://www.nap.edu/resource/25467/09252019Social\\_Care\\_recommendations.pdf](https://www.nap.edu/resource/25467/09252019Social_Care_recommendations.pdf), <https://www.healthypeople.gov/2010/hp2020/advisory/SocietalDeterminantsHealth.htm>, [https://www.who.int/health-topics/social-determinants-of-health#tab=tab\\_1](https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1)). Effectively meeting needs requires not only identifying relevant resources, but also expanding the healthcare workforce to better address needs, and developing linkages between health systems and community organizations that provide social support.

Many examples of interventions to address SDOH have been reported (<https://health.gov/healthypeople>, <https://www.cdc.gov/socialdeterminants/cdcprograms/index.htm>).<sup>1</sup> These interventions have largely focused on targeted areas: housing, employment, education, food security, social/community context, and transportation.<sup>2–4</sup>

Yet many of these efforts have omitted a vital contributor to health outcomes: caregiving (<https://www.rolereversalsblog.com/blog/2020/2/17/should-caregiving-be-considered-a-social-determinant-of-health>). Understanding a person’s caregiving context is critical for three reasons. First, the care patients receive in their homes—including unpaid informal care provided by family or friends, and care delivered by paid trained home care providers—has a significant influence on patient outcomes;<sup>5</sup> for example, patients with more unmet caregiving needs have higher hospital readmission rates<sup>6</sup> and are more likely to move to a nursing home or to die, than those whose care needs were met.<sup>7</sup> Factors including whether a person lives with their caregiver, and the degree of caregiver burden, are associated with worse heart failure symptoms and quality of life,<sup>8</sup> and are predictive of nursing home placement for older adults and persons with dementia.<sup>9,10</sup> While the degree to which caregiver burden impacts institutionalization is unclear, interventions to improve caregiver well-being delay nursing home placement of persons with Alzheimer’s disease.<sup>7,11,12</sup> Second, informal caregivers themselves are at greater risk for poor health outcomes<sup>13,14</sup> and are more likely to have impaired personal health behaviors, such as neglecting their own health.<sup>15</sup> Up to a third of caregivers view their own health as fair or poor,<sup>16</sup> an assessment that worsens with increasing duration of caregiving.<sup>17,18</sup> The 2016 National Academies report, Families Caring for an Aging America (<https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america#>), documents the negative health impacts experienced

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by family caregivers, serving as a call to action. Informal caregivers often do not have access to resources to help with, or financial benefits for, caregiving activities. The estimated value of these unpaid activities was \$470 billion in 2019 (<https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>). Even formal caregivers face risks as underpaid and low-benefit care providers. Third, it is essential to understand how care occurs in the home to achieve effective care coordination. By omitting caregiving from assessments of SDOH, health systems and clinicians miss an important opportunity to improve engagement in care, care delivery effectiveness, care plan adherence, and caregiver and care recipient health outcomes. Family caregivers disconnected from clinicians cannot reinforce treatment plans. Supporting family caregivers and integrating them into the healthcare team can offset the negative impacts of caregiving-related social determinants.

Just as COVID-19 underscored the impact of SDOH on outcomes, and the vulnerability of many groups within the USA, it also highlighted the susceptibility of formal and informal caregivers.<sup>16</sup> Even prior to the pandemic, caregivers were more likely to report isolation, depression, and anxiety (<https://www.caregiver.org/resource/caregiver-statistics-health-technology-and-caregiving-resources/>). The need to consider their own health risks, and those of their care recipients, increases caregivers' perceptions of social isolation, worsening their mental health.<sup>19</sup> For example, surveys conducted early in the pandemic found that caregivers were 3.3 times as likely to have started or increased substance use as non-caregivers.<sup>20</sup> Continued uncertainty about variants and safe activities may lead to prolonged negative impacts despite vaccine availability.

Caregiving intersects with other SDOH among underrepresented groups. Health inequities experienced by Black, Indigenous, and People of Color (BIPOC) extend to caregiving, as caregiving activities and access to resources differ depending on people's positions in society. Black persons over 65 are 30% more likely to be formal and informal caregivers than Whites, Latinos are more likely to provide home-based informal care to family members, and caregivers of color are more likely to experience worse health outcomes (<https://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity>).<sup>21,22</sup> Decreased access to care for BIPOC care recipients and caregivers, and differential resource access, both contribute to worse outcomes. While updated data on caregiving in the pandemic are limited, the most recent Caregiving in the US: 2020 report noted that compared with informal caregivers in other racial/ethnic groups, African American caregivers are more often unmarried, are employed outside of the home, live with their care recipient, and are more likely to report financial challenges ([https://www.caregiving.org/wp-content/uploads/2020/05/AARPI316\\_CGProfile\\_AfricanAmerican\\_May7v8.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/AARPI316_CGProfile_AfricanAmerican_May7v8.pdf)).

Based on the evidence regarding the impacts of caregiving on caregivers' and care recipients' health outcomes, and on our collective experience with research and clinical care, we recommend four strategies that health systems can undertake to better assess caregiving as important SDOH, mitigate the health impact of formal and informal caregiving, and improve caregiver and care recipient outcomes.

First, health systems must support system-level changes to formally recognize and identify caregivers, incorporate them into care plans, and document this information in health records (<https://www.nap.edu/resource/23606/Caregiving-RiB.pdf>). Accomplishing this requires talking about caregiving. Asking patients both for whom they care, and from whom they receive care, is critical to understanding their social circumstances. Reducing the invisibility of caregivers is necessary, but is complicated because many informal caregivers do not consider themselves "caregivers." Talking about caregiving activities is a first step for understanding each person's caregiving context. A second step is to assess the needs of families who provide informal caregiving. This can be accomplished by consistently collecting (and updating) information about caregiving activities in patient medical records as is done for other SDOH, including hours spent providing care, caregiving intensity, and strain.

Integrating caregivers into care plans improves outcomes.<sup>6,23,24</sup> Caregivers are currently excluded in multiple ways. At a basic level, they are often physically excluded from discussions, even if unintentionally. Attending daytime outpatient appointments is difficult for caregivers who work, are in school, or have young children. In hospitals, inpatient teams are often absent during the evening and weekend times most convenient for caregivers. Care team huddles that loop in caregivers by phone could be a powerful approach for coordinating care.<sup>25</sup> Harnessing the advantage of virtual visits and asynchronous communication may support caregivers' involvement in care discussions.

More data regarding effective ways to support and integrate caregivers are needed. However, limited evidence in targeted populations does demonstrate the importance of these supports ([https://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse\\_198208.pdf](https://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_198208.pdf)). Care Interventions for People Living with Dementia and the Caregivers, an Agency for Healthcare Research and Quality comparative effectiveness review ([https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/cer-231-dementia-interventions-final\\_0.pdf](https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/cer-231-dementia-interventions-final_0.pdf)), identified two promising multi-component interventions that improve caregiver and recipient outcomes: Collaborative Care<sup>26</sup> and Resources for Enhancing Alzheimer's Caregiver Health (REACH).<sup>27</sup>

Second, we need a broad, coordinated scale-up of policies to support caregivers as part of our strategy to improve caregiver and recipient health outcomes. Coordinating care is often overwhelming for informal caregivers and could be improved by navigators, case managers, and advocates.<sup>28</sup>

Transportation or travel reimbursement, support groups, skills training, and respite care are examples of ways that health systems can directly support caregivers. Enhanced access to health information through effectively designed portals that endorse patient preferences for caregiver access while maintaining patient privacy and HIPAA requirements could better equip caregivers to understand care plans and communicate with clinicians.<sup>29</sup> These efforts should be undertaken with a focus on digital equity so as to avoid exacerbating disparities in health care access. Health systems should partner with caregivers to understand and provide the supports that are most relevant for those they serve.

The Department of Veterans Affairs has undertaken several noteworthy initiatives that are examples of coordinated policies. The Caregiver Support Program (CSP) has established caregiver-specific points of contact at each VA medical center to connect caregivers with the health system. Caregiver coordinators help caregivers navigate community-based supports. Recently, COVID-19 vaccinations were expanded to include caregivers.<sup>30</sup> Within CSP, the Program of Comprehensive Assistance for Family Caregivers (PCAFC) ([https://www.caregiver.va.gov/support/New\\_CSC\\_Page.asp](https://www.caregiver.va.gov/support/New_CSC_Page.asp)) provides financial support for informal caregiving activities. The PCAFC's initial focus on post-9/11 veteran caregivers limited its reach, but it is among the most comprehensive caregiver support models yet implemented, and does appear to have increased non-institutional care. The VA Aid & Attendance Benefit helps defray the cost of long-term care, but is limited to veterans receiving pensions (<https://www.va.gov/pension/aid-attendance-housebound>).

Third, we must incorporate the topics of "caregiving" and "inclusive care"<sup>23</sup> into health professions' educational curricula. So often, clinicians look into a patient room, see a large number of family members, and feel overwhelmed and unprepared to effectively communicate regarding uncertain situations. Instead, we have the opportunity to cultivate a mindset of seeing caregivers as extensions of the care team who will enable developing and enacting care plans. Initiatives like the Campaign for Inclusive Care promote this shift in thinking (<https://campaignforinclusivecare.elizabethdolefoundation.org>).<sup>31</sup> Efforts to improve clinicians' skills in partnering with caregivers must be systematically applied, and married to system and policy changes noted above so that clinicians' attempts to engage caregivers are recognized as part of the work of usual care and operationally supported (<https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america#>).

Fourth, health systems must develop robust partnerships with community programs and organizations that support caregivers.<sup>2</sup> A public health approach to meeting caregiver needs could reduce unmet needs and improve caregiver and care recipient outcomes ([https://www.rosalyncarter.org/wp-content/uploads/2020/10/RCI\\_Recalibrating-for-Caregivers\\_2020.pdf](https://www.rosalyncarter.org/wp-content/uploads/2020/10/RCI_Recalibrating-for-Caregivers_2020.pdf)). Coordination between public health agencies,

area agencies on aging, non-profits, and the health care system is critical to support caregivers. Veteran Community partnerships, such as the Hidden Heroes City Campaign, are examples that empower collaborative action between VA and community partners to develop and expand personalized options for veterans and caregivers (<https://www.va.gov/healthpartnerships/vcp.asp>, <https://hiddenheroes.org/hidden-heroes-cities-and-counties/>). The Veteran Directed Care Program (VDC), established as a VA/Administration for Community Living partnership, helps veterans eligible for nursing home care and their caregivers obtain needed services in their own homes (<https://acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based>). Local public health agencies have also served as conveners of collaborations to support local communities.<sup>32</sup> Other local health system and community partnerships provide examples of successful partnership models.<sup>33</sup> Current inequities in available community resources will need to be identified and addressed.

Implementing these recommendations will be challenging, requiring coordinated action across multiple actors, from the local to the national level. Our four health system recommendations should be coupled with legislation that financially supports caregiving activities and expands community-based services. In Families Caring for an Aging America, the National Academies called for a National Family Caregiver Strategy encompassing specific initiatives with regard to caregiver identification, payment reform, training, and national data collection infrastructure (<https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america#>). These recommendations remain largely unrealized. Legislative action could support the provision of an expanded group of caregiver support services. The Biden administration's proposed American Families Plan would create a national comprehensive paid family and medical leave program (<https://www.whitehouse.gov/briefing-room/statements-releases/2021/04/28/fact-sheet-the-american-families-plan/>). This program would support informal family caregivers for up to 12 weeks and would provide child care support that could benefit both informal family and formal caregivers. However, it does not address long-term caregiving activities often provided by family caregivers, and does not support those who are not employed outside the home. These are major omissions requiring further policy actions. Implementing solutions that reduce, rather than increase, health inequities for BIPOC caregivers is critical; expanding access to services for disadvantaged populations is necessary.

In summary, the need to mitigate the influence of SDOH on health outcomes and inequities has been recognized. Caregiving is an under-recognized, under-addressed contextual factor that significantly influences the health of recipients and caregivers. We suggest four health system actions to reduce negative outcomes associated with caregiving, and achieve better outcomes for individuals and more equitable

care across communities. Committing to these efforts, and to ongoing evaluation of their implementation, will allow us to identify best practices at organizational, local, and national levels, and better understand how investments in integrated caregiving and care delivery are reflected in downstream costs, utilization, and improved patient and caregiver outcomes (<https://timesupnow.org/care-economy-business-council/>).

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### Declarations

**Conflict of Interest** *The authors declare that they do not have a conflict of interest.*

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