

ENGAGING AND SUPPORTING FAMILY CAREGIVERS IN CARE DELIVERY

A Roger C. Lipitz Center for Integrated Health Issue Brief

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INTRODUCTION

Millions of Americans manage basic health and functioning needs with the help of family and unpaid caregivers. Family caregivers--defined as relatives, partners, or friends who help due to personal relationship rather than financial compensation--arrange and attend medical appointments, participate in routine and high-stakes treatment decisions, coordinate care and services, help with daily tasks such as dressing and bathing, manage medicines, obtain and oversee the use of medical equipment, handle bills and banking, and ensure that food and shelter needs are met.

The availability and adequacy of family caregiver support has important consequences for quality of life, services used, and the quality and costs of care among those who rely on their help. Family caregivers are not typically identified, assessed, or supported in care delivery. At a most basic level, family caregivers are often unable to access information about patient health and treatments that is necessary to coordinate and deliver safe and appropriate care. More broadly, health care professionals do not typically assess caregivers' knowledge, understanding, or proficiency in the tasks they are expected to perform. Family caregivers describe learning how to provide care by trial and error—and being fearful of making mistakes that may cause harm. Current medical practice too often fails to include caregivers in treatment decisions and care planning while assuming they are willing and able to carry out the plan of care.

Faculty at the Roger C. Lipitz Center for Integrated Health Care, based in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health, are leading initiatives to better understand the needs and strengthen support afforded to individuals with complex medical needs and their caregivers. These initiatives involve contributing new knowledge, collaborating with decision makers, and developing and testing models of care to support individuals with complex health needs and their care partners.





CONTRIBUTING NEW KNOWLEDGE

The Center has had a foundational role in establishing and sustaining the National Institute on Aging (NIA)-supported National Study of Caregivers (NSOC), which periodically gathers information on family and unpaid caregivers who are assisting participants in the National Health and Aging Trends Study (NHATS). Together, NHATS and NSOC provide the only national data on caregiving that offer linked caregiver and recipient perspectives.

Drawing on these data, Center affiliates are conducting original research to characterize the “invisible work” of family caregivers, the circumstances under which they provide care, and the consequences of their effort to individuals, families, and society. For example, Center affiliates have documented notable race and ethnic inequities in caregiving circumstances, receipt of post-hospitalization training from health professionals, and respite use. Research led by Chanee Fabius, PhD, assistant professor in the Department of Health Policy and Management, finds that Black family caregivers are more likely to provide in excess of 40 hours of care per week to older adults who have more extensive care needs and limited financial resources but less likely to use respite. Health Services Research & Policy (HSR&P) doctoral student, Linda Chyr, finds Black older adults with disability are less likely to transition to nursing homes.

Former HSR&P trainee, Julia Burgdorf, now at the VNSNY Center for Home Care Research, finds that just one in ten family caregivers receives role-related training and that caregivers with lower socioeconomic status are less likely to receive training to assist with a post-hospital care transition. Within the context of Medicare-funded home health, she finds one in three family caregivers has unmet training needs, which may heighten the resource intensity of home health care and risk of subsequent hospitalization among those they help.

Jennifer Wolff, PhD, Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and director of the Roger C. Lipitz Center for Integrated Health Care, demonstrates that family caregivers commonly are present and engaged in navigating health system demands. Although caregivers providing substantial assistance with health care activities are more likely to experience significant role-related challenges, few use supportive services or are asked about needed help, including at end-of-life. Importantly, she and colleagues have found the preparedness of caregivers affect older adults' use of emergency, acute, and long-term services.

Through the newly established Hopkins Economics of Alzheimer's Disease and Services (HEADS) Center, Lipitz Center affiliates convened a workshop for early-stage scientists designing studies relating to family and unpaid caregiving to persons with dementia.



POLICY IMPACT

Federal and State policy makers are developing strategies to systematically recognize and support family caregivers through such efforts as the [RAISE Family Caregiving Advisory Council and State Caregiving Plans](#). Center affiliates are contributing by informing policies and best practices.

Data from the [National Study of Caregivers](#) were used throughout the National Academy of Sciences, Engineering, and Medicine Consensus report, [Families Caring for an Aging America](#), and its recommendations for research, policy, and practice. Center affiliates are addressing recommendations from this report, such as partnering with Catherine Riffin, who [convened](#) thought leaders to develop recommendations on best practices for engaging family and other unpaid caregivers of persons with dementia in care delivery, and serving in an advisory capacity to the National Academy for State Health Policy RAISE Family Caregiver [Resource and Dissemination Center](#).

Wolff served as a member on the National Academy of Sciences, Engineering, and Medicine Consensus Committee that produced the 2021 report, [Meeting the Challenge of Caring for Persons Living With Dementia and Their Care Partners and Caregivers](#). She co-chaired, with David Reuben, MD, director of the Multicampus Program in Geriatrics Medicine and Gerontology and chief of Division of Geriatrics at the University of California, Los Angeles Center for Health Sciences, the [2020 National Institute on Aging Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers](#) to identify related research priorities.

Center affiliates led the development of a report, [In Support of Family Caregivers: A Snapshot of Five States](#), co-sponsored by The John A. Hartford Foundation and the Milbank Memorial Fund, to identify innovative state-based programs and policies to better support family caregivers. This report helped inform the Center for Health Care Strategies' ongoing [initiative](#), Helping States Support Family Caregivers Caring for an Aging America. The new initiative, underway in partnership with eight states, seeks to strengthen family caregivers' capacity, establish robust data collection systems, and build cross-sector partnerships.

Faculty have contributed their [perspectives](#) and [evidence](#) to active national and state dialogues surrounding whether and how to structure paid family leave policies to support working caregivers.



APPLIED INTERVENTIONAL INITIATIVES

Well-coordinated, team-based care is foundational in delivery of services that are safe, efficient, and of higher quality. Although family caregivers commonly attend medical encounters, participate in routine and high-stakes treatment decisions, and support treatment adherence and care coordination, few care delivery efforts have sought to proactively establish stronger and more effective partnerships with family caregivers. Center affiliates are leading embedded



interventional studies and demonstrations within care delivery settings to contribute knowledge on scalable models of care and organizational initiatives to set the stage for widespread diffusion.

Two NIA-funded embedded trials, an efficacy study entitled “SHARE” and a pragmatic study, “SHARING Choices,” led by Wolff and Sydney Dy, MD, MAS, are evaluating the effects of a multicomponent communication intervention to engage family caregivers in advance care planning for older adults with cognitive impairment in primary care. These studies are ongoing in strong partnership with two organizations, Johns Hopkins Community Physicians and MedStar Health System.

A John A. Hartford Foundation-funded initiative led by Wolff and Cait DesRoches of OpenNotes and Harvard Medical School, Engaging Family Caregivers through Shared Access to the Electronic Health Record, is evaluating the spread of organizational strategies to increase uptake of patient portal use by care partners of older adults at three geographically diverse health systems. A learning collaborative for health care organizations is being convened with the goal of disseminating best practices and lessons learned to facilitate scaling.

New work, supported by the NIA-funded Johns Hopkins Alzheimer’s Disease – Resource Center for Minority Aging Research and IMPACT Collaboratory led by Fabius, describes Maryland-based home care agencies and identifies strategies to improve coordination between the direct care workforce and family caregivers of people living with dementia.

A new five-year, National Institute on Aging-funded Leadership Award to Wolff convenes an interdisciplinary group of talented social scientists and clinician-scientists from Johns Hopkins and external institutions to better understand and address the needs of caregivers of persons living with dementia through scaling consumer health information technology innovations, such as person-family agenda-setting and OurNotes.

Wolff is collaborating with DesRoches and ARCHANGELS on a new three-year grant from the Ronald C. Wilson Junior Foundation to develop and test pilot interventions for 1) identifying and pinpointing the needs of individual caregivers and 2) connecting them to needed services, when appropriate.





SELECT PUBLICATIONS

Center policy and research initiatives are supported and elevated by peer-reviewed publications, a selection includes:

Burgdorf JG, Fabius CD, Riffin C, Wolff JL. Receipt of Posthospitalization Care Training Among Medicare Beneficiaries' Family Caregivers. JAMA Netw Open. 2021 Mar 1.

Burgdorf J, Roth DL, Riffin C, Wolff JL. Factors Associated With Receipt of Training Among Caregivers of Older Adults. JAMA Intern Med. 2019 Jun 1.

Burgdorf JG, Stuart EA, Arbaje AI, Wolff JL. Family Caregiver Training Needs and Medicare Home Health Visit Utilization. Med Care. 2021 Apr 1.

Burgdorf JG, Arbaje AI, Stuart EA, Wolff JL. Unmet family caregiver training needs associated with acute care utilization during home health care. J Am Geriatr Soc. 2021 Jul.

Fabius CD, Wolff JL, Willink A, Skehan M, Mulcahy J, Kasper J. Community-Based Long-Term Services and Supports: Are the Needs of Older Adults and Their Caregivers Being Met? The Commonwealth Fund. 2021 Oct 27.

Fabius CD, Wolff JL, Kasper JD. Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans. Gerontologist. 2020 Sep 15.

Freedman VA, Bandeen-Roche K, Cornman JC, Spillman BC, Kasper JD, Wolff JL. Incident Care Trajectories for Older Adults with and without Dementia. J Gerontol B Psychol Sci Soc Sci. 2021 Dec 10.

Parker LJ, Fabius CD. Racial Differences in Respite Use among Black and White Caregivers for People Living with Dementia. J Aging Health. 2020 Dec.

Wolff JL, Spillman BC, Freedman VA, Kasper JD. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. JAMA Intern Med. 2016 Mar.

Wolff JL, Freedman VA, Ornstein KA, Mulcahy JF, Kasper JD. Evaluation of Hospice Enrollment and Family and Unpaid Caregivers' Experiences With Health Care Workers in the Care of Older Adults During the Last Month of Life. JAMA Netw Open. 2020 Apr 1.

Wolff JL, Freedman VA, Mulcahy JF, Kasper JD. Family Caregivers' Experiences With Health Care Workers in the Care of Older Adults With Activity Limitations. JAMA Netw Open. 2020 Jan 3.

Wolff JL, Aufill J, Echavarria D, Blackford AL, Connolly RM, Fetting JH, Jelovac D, Papathakis K, Riley C, Stearns V, Zafman N, Thorner E, Levy HP, Guo A, Dy SM, Wolff AC. A randomized intervention involving family to improve communication in breast cancer care. NPJ Breast Cancer. 2021 Feb 12.



IN THE MEDIA

The Center's experts are trusted sources in the media and often contribute to news stories.

- Fabius and Halima Amjad were interviewed by the [GeriPal](#) podcast on “All Things Caregivers” regarding the needs of caregivers, health policy issues in support for caregivers, and clinical issues related to caregiver identification and capacity.
- Fabius was an invited panel member at the [Investing in Brain Health Equity with Paid Family & Medical Leave Briefing](#) at the USAgainstAlzheimer's 2021 Virtual Summit.
- Burgdorf's work on gaps in training of family caregivers was featured in various outlets, including [Forbes](#) and [Reuters](#).
- Wolff presented at policy conferences on aging and disability and her work on caregiver interactions in care delivery is featured in interviews by the [JAMA Network](#), as well as by mainstream [media outlets](#) such as [AARP](#), [The Washington Post](#) and [The New York Times](#).

ACKNOWLEDGMENTS

The issue brief was written by [Jennifer Wolff](#), PhD, Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and director of the Roger C. Lipitz Center for Integrated Health Care and [Chanee Fabius](#), assistant professor, and designed by Munin Streitz and Caitlin Hoffman, communications staff who support the Center at the Johns Hopkins Bloomberg School of Public Health.