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### Title

New Directions to Advance Family Caregiving Research

### Permalink

<https://escholarship.org/uc/item/3d52h6k8>

### Journal

The Gerontologist, 60(Supplement\_1)

### ISSN

0016-9013

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### Publication Date

2020-02-14

### DOI

10.1093/geront/gnz182

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Peer reviewed

## Editorial

# New Directions to Advance Family Caregiving Research

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## Abstract

This supplement describes the content, processes, and outcomes of the Research Priorities in Caregiving Summit convened by the Family Caregiving Institute (FCI) at the Betty Irene Moore School of Nursing at UC Davis in March 2018. As described in the editorial introduction and the supplement's four papers, the summit sought to integrate and cross-pollenate the already compendious work on family caregiving to describe ways forward in the field. Thought-provoking commissioned synthesizing papers on issues of heterogeneity and trajectories of caregiving and its cultural embeddedness and on the potential of technology to shape and enhance caregiving interventions set the stage for a highly disciplined, multistaged process that resulted in the drafting of a set of research themes and priorities that were later finalized by faculty at the FCI.

This supplement issue, “Advancing Family Caregiving Research,” presents the proceedings from a 2-day invitational meeting titled, “Research Priorities in Caregiving Summit,” convened by the Family Caregiving Institute (FCI) at the Betty Irene Moore School of Nursing at UC Davis. The proceedings call out caregiving intervention research as a special focus, not because it has been unappreciated, unacknowledged, or understudied, and not because there are not legions of researchers, clinicians, advocates, and policy makers engaged in the topic. Rather, as the papers in this supplement illustrate, the traditional and highly productive strategies of the constituencies that contribute to caregiving intervention research have been and continue to be particularly generative in pointing out fruitful directions for this work. The proceedings consist of four articles, including a detailed overview of the 2-day summit (Harvath et al., 2020); the other three articles reflect the specific topics that served as an organizing framework for the summit.

## Editorial Reflections

Before speaking directly about the articles in this supplement, we want to set the stage, unpacking aspects of gatherings and summits—such as this FCI convening—that are critically important to the incubation of great ideas. What makes these gatherings important and effective is

their difference from our normal pursuits as individual researchers and research teams; these sorts of convenings nurture the kind of collective and expansive thinking needed to further elucidate the complex problems we face. They depend upon participants bringing multiple perspectives and lenses to the table, as we build programs, practices, and policies that fully support the central role of family caregiving and the health and well-being of older adults and their caregivers. We begin by sharing our first-hand experience as summit participants and highlight the unique opportunities—looking ahead—to leverage the spirit of shared collaboration and collective wisdom that emanated during those two intellectually invigorating days.

To start, we were among more than 50 individuals from service agencies, funding organizations, and academia, all coming together for this invitational summit; there was a mix of disciplines, types of agencies/organizations, experience in academia, including junior researchers (e.g., doctoral students and post-docs), longstanding caregiver researchers, and other experienced researchers expanding their work to include family caregiving. The gathering was generative precisely *because* there was a generous and forthright sharing of the best—not the second-best—ideas, and the genuinely insightful—not just clever—ideas. There was a felt sense of collaboration: researchers and experts from practice/service arenas talking together and

identifying long-standing—or newly appreciated—gaps in caregiver inquiry and services and exploring ways to tackle these gaps and consider priorities for how we use resources to support research in this area. This was a place to think deeply and broadly, with each of us leveraging our individual experience, expertise, and passions to identify, challenge, and synthesize ideas and directions in a way that we can all draw upon as we go back to our separate “home turfs.”

## Highlights of the Summit Process

### Organizing Topics for the Summit

The FCI commissioned briefing papers for the four organizing topics for the summit (heterogeneity, trajectory, and multicultural needs of family caregivers, and technology); these were presented at the start of the summit. The four topics stemmed from FCI faculty and staff reviews and syntheses of gaps reported across recent national expert reports and convenings. The papers were expansive, generalized, speculative, not altogether tethered to hard evidence, deliberately provocative—and meant to be challenged. The papers offered just enough content to prompt us to begin thinking critically about each topic and to serve as a springboard for the brainstorming activities that followed (see Harvath et al. [2020] on how topics were identified).

Three of the articles included in this supplement stem from the briefing papers, with content related to the multicultural needs of family caregivers incorporated into each of the three papers.

Across the three articles that flowed from the summit domains, *context* and *individual characteristics* emerge as recurrent themes, prompting us to delve into the who, what, where, when, and why of family caregiving as we design and report on intervention research. Two articles present conceptual frameworks to guide researchers in designing intervention programs, considering trajectories of dementia-specific caregiving (Gallagher-Thompson et al., 2020) and adoption of technology-enabled innovations to support caregiving (Lindeman, Kim, Gladstone, & Apesoa-Varano, 2020). Young and colleagues (2020) report findings from a review of systematic reviews of the broader spectrum of family caregiving intervention research, noting important gaps in selecting samples and collecting and/or reporting sample characteristics, and implications for interpreting the results of systematic reviews as a basis for generalizing research findings to diverse populations. Each article offers insights into the reciprocal, interconnected nature of caregiving, the complexities of person–environment fit, and importance of *cultural values and beliefs*, whether designing caregiving intervention research that considers the timing for an intervention (i.e., early, mid, or late-stage trajectory of disease), technology or technology-enabled innovation, or attention to individual caregiver/care recipient characteristics, disease conditions, and, specifically,

social determinants of health. All three articles call out the inadequacies of a *one-size-fits-all approach* which is common across intervention research; all reinforce the need for more customized approaches.

Gallagher-Thompson and colleagues (2020) offer a dementia-specific conceptual framework that reflects the trajectories of the person living with a dementing illness (care recipient), the person(s) providing unpaid care to that person (carer or caregiver), and care recipients' interface with health care systems, all embedded within the broader sociocultural context comprised of both the care recipient/caregivers' heritage culture and the cultures of health care systems and their providers. The authors call for customizing intervention research to consider individual characteristics, stages of disease, and related caregiving demands and interface with health systems. They identify key transition points triggered by changes in care recipient needs (e.g., transitions between care settings). They offer ways to use the conceptual framework as a guide for research along the caregiving trajectory and potential research projects. And finally, acknowledging this “exceedingly complex area of research” (Gallagher-Thompson et al., 2020, p. S29), they invite feedback to continually refine the usefulness of the framework and consider applications of the framework beyond dementia-specific caregiving.

Lindeman and colleagues (2020) offer a research framework for promoting consumers' access to and adoption of technology-enabled caregiving interventions and achieving positive outcomes for family caregivers and care recipients. Consistent with the underpinnings of a person–environment fit perspective, the authors highlight contextual factors to consider when designing technology-enabled innovations research, including individual, socioeconomic, and technological moderators and the mediators that may hinder or facilitate access to and benefits of these interventions. Using the framework as a guide, the authors propose priority research topics related to key moderators and mediators and to measurement.

Young and colleagues (2020) focus on the diverse and heterogeneous characteristics of family caregivers and care recipients, reporting findings from their review of systematic reviews of interventions for older adults with age-related chronic conditions for inclusion of specific population characteristics commonly associated with disparities. Their findings reveal inconsistencies and gaps in reporting the heterogeneity of the samples included in original studies, especially the characteristics of the samples that are commonly linked to social determinants of health and disparities, and a focus on dementia over other conditions. The authors highlight the need for research that incorporates and reports the contextual features of caregiving that contribute to health disparities as well as other distinctions that reflect the diverse and heterogeneous needs of caregivers such as the care recipient's condition and phase (acute/chronic), the extent of caregiving family networks, and caregiver health. They also call for common

data elements to advance cross-study comparisons, a recommendation also put forth by [Gallagher-Thompson and colleagues \(2020\)](#).

The lead article by [Harvath and colleagues \(2020\)](#) showcases the intentionality of the summit's structure, providing a detailed account of summit processes, beginning with the presentation of the four briefing papers that served as an organizing framework for the summit, followed by a sequence of activities over 2 days—brainstorming, synthesizing, narrowing, and consensus-building—to achieve the stated outcome: to develop Caregiving Research Priorities and Priority Statements. Foundational to the activities that followed, the brainstorming session was organized using a world café approach and facilitator-led workstations for each of the four briefing paper topics presented at the start of the summit: heterogeneity, trajectory, and multicultural needs of family caregivers, and technology. As we moved from one workstation to the next, we were encouraged to fully embrace an expansive approach and not play it safe by filtering our ideas and stopping at the usual suspects; we were prompted to bring our “*most important*” ideas, as well as “*the “wild and crazy” ideas that may also have merit*” (p. S5). We took this encouragement to heart, and as one might imagine, the brainstorming sessions yielded rich and comprehensive lists of ideas, with something for everyone.

### Caregiving Research Priorities and Priority Statements

Following the brainstorming activities, the FCI faculty and staff guided the workstation facilitators and topic leads through a daunting process of synthesizing each of the vast lists generated by the brainstorming into 8–10 key themes for the larger group to review and prioritize. At that point, it was difficult to imagine how we could condense these lists without losing the details and nuances that emerged during the brainstorming sessions. This is where we were advised to *trust the process*, assured that the rich detail would reappear later in other activities—which it did—as we drafted one to two page Priority Statements for each of the Research Priorities.

The Research Priorities and Research Statements that emerged from the Summit offer concrete directions for novice and well-established researchers to design family caregiving intervention research that addresses the most urgent gaps in the literature. These 10 research priorities offer a roadmap for future research that will address gaps in the vast literature currently available. A summary listing of each priority is outlined in the [Harvath et al. \(2020, p. S5\)](#) paper—and warrants highlighting again here:

1. Evaluate technologies that facilitate choice and shared decision making.
2. Determine where technology is best integrated across the trajectory of caregiving.
3. Evaluate family-centered adaptive interventions across conditions, situations, stages, needs, preferences, and resources.
4. Examine the heterogeneity of attitudes, values, and preferences toward caregiving, services, and supports.
5. Evaluate family caregiver interventions in ways that address real-world complexity, translation, scalability, and sustainability.
6. Develop a conceptual framework and typology of the trajectory of caregiving for novel interventions and outcomes.
7. Conduct risk/needs assessment of the changing needs of family caregivers over the trajectory of caregiving.
8. Conduct implementation research on evidence-based caregiving programs for diverse populations.
9. Develop outcome measures that are relevant to family caregivers from diverse social and cultural groups.
10. Develop research methodologies that account for the complex structures of informal caregiving.

Additional details for each priority are available at: [https://health.ucdavis.edu/nursing/familycaregiving/pdfs/Updated\\_Research\\_Priorities\\_Jan2019.pdf](https://health.ucdavis.edu/nursing/familycaregiving/pdfs/Updated_Research_Priorities_Jan2019.pdf)

### Closing Remarks and a Call to Action

The proceedings in this supplement leverage the vast knowledge generated over past decades about caregiver interventions and built on the strategic work reflected in the *Families Caring for an Aging America* report ([National Academies of Sciences Engineering and Medicine, 2016](#)) and several convenings held in recent years. The summit papers and conversations also benefited from an increasing appreciation of the importance of developing and studying interventions that engage end-users, are grounded in stated mechanisms of action, and that proceed in an intentional, staged manner (see [Onken et al. \(2014\)](#)).

In a spirit of collaboration, we placed our individual interests and programs of research aside to focus on directions for the field of family caregiving research—as a whole—with an overarching aim to enhance the health and well-being of family caregivers and care recipients. As you read the articles in this supplement, we encourage you to embrace the same spirit of collaboration we experienced at the Summit. Explore new ways to conceptualize your work and engage with new colleagues to continue the momentum of thinking broadly about how we can, collectively, move the field forward, and work together in new ways. Consider, for example, innovative collaborations and partnerships for your own work—beyond your usual teams—to tackle the very challenging and complex aspects of advancing intervention research in family caregiving that most of us encounter.

The supplement highlights the complexities of our work. Incorporating the contextual and individual characteristics of caregivers and care recipients can get quite

messy, affecting budgets, timelines, and study designs. We may find ourselves gravitating back to “low-hanging fruit,” approaches we have used for prior successful proposals and not venturing to more dangerous innovative territories. In addition, the summit’s academic participants, both junior and senior, repeatedly reminded us of the reality of the tenure and promotion journey and raised questions about how collaboration, especially the sharing of strikingly novel research ideas, can advance the careers of junior researchers. The summit offered no answers to these questions, but its spirit and processes did suggest that supporting research incubator and peer- or mock-review networks and mechanisms and engaging in shared authorial endeavors could both act to the benefit of these emerging leaders and propel the larger conversation forward.

Beyond caregiving intervention research, the Summit proceedings highlight important issues about the need to integrate policy and micro and macro system-level considerations into family caregiving research. Similarly, they underscore the importance translating evidence-based best practices at policy and systems levels; we need to ask, “What are the policy and system level changes that will be needed to support and reinforce use of best practices when working with family caregivers and care recipients?” A national scan of the CARE Act implementation highlights the need for best practices to operationalize the CARE Act and successfully implement family caregiver support programs (Reinhard, Young, Ryan, & Choula, 2019). Efforts to operationalize the Affordable Care Act have illustrated the structural system-level challenges that must be addressed as part of our caregiving research.

This supplement stands as an acknowledgement of the FCI for convening the Summit and for their well-thought out approach that achieved both breadth and depth of directions for next steps in family caregiving research, identifying and gaining consensus for intervention research priorities, stemming from four broad topics: heterogeneity, trajectory, technology, and multicultural needs related to caregiving.

We particularly want to acknowledge the support of the Gordon and Betty Moore Foundation to the FCI which made possible the Summit and publication of this supplement.

## Funding

This paper was published as part of a supplement sponsored and funded by the Gordon and Betty Moore Foundation.

## Conflict of Interest

Dr. Siegel is funded by the Family Caregiving Institute through a grant from the Gordon and Betty Moore Foundation (#5968).

## References

- Gallagher-Thompson, D., Bilbrey, A. C., Apesoa-Varano, E. C., Ghatak, R., Kim, K. K., & Cothran, F. A. (2020). The caregiving trajectory: Opportunities for future research and practice. *The Gerontologist*, 60(S1), S29–S40. doi:10.1093/geront/gnz157
- Harvath, T. A., Mongoven, J. M., Bidwell, J. T., Cothran, F. A., Sexson, K. E., Mason, D. J., & Buckwalter, K. C. (2020). Research priorities in family caregiving: Process & outcomes of a conference on family-centered care across the trajectory of serious illness. *The Gerontologist*, 60(S1), S5–S13. doi:10.1093/geront/gnz138
- Lindeman, D., Kim, K. K., Gladstone, C., & Apesoa-Varano, E. C. (2020). Technology and caregiving: Emerging interventions and directions for research. *The Gerontologist*, 60(S1), S41–S49. doi:10.1093/geront/gnz178
- National Academies of Sciences Engineering and Medicine. (2016). *Families Caring for an Aging America*. Washington, DC: The National Academies Press. Retrieved from <http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx>
- Onken, L. S., Carroll, K. M., Shoham, V., Cuthbert, B. N., & Riddle, M. (2014). Reenvisioning clinical science: Unifying the discipline to improve the public health. *Clinical Psychological Science*, 2, 22–34. doi:10.1177/2167702613497932
- Reinhard, S. C., Young, H. M., Ryan, E., & Choula R. (2019). *The CARE Act Implementation: Progress and Promise*. Washington, DC: AARP Public Policy Institute. Retrieved from <https://www.aarp.org/ppi/issues/caregiving/>
- Young, H. M., Bell, J. F., Whitney, R. L., Ridberg, R. A., Reed, S. C., & Vitaliano, P. P. (2020). Social determinants of health: Underreported heterogeneity in caregiving intervention systematic reviews. *The Gerontologist*, 60(S1), S14–S28. doi:10.1093/geront/gnz148