

Forum

## Research Priorities in Family Caregiving: Process and Outcomes of a Conference on Family-Centered Care Across the Trajectory of Serious Illness

Theresa A. Harvath, PhD, RN, FAAN, FGSA,<sup>1,\*</sup> Jennifer M. Mongoven, MPH,<sup>1</sup> Julie T. Bidwell, PhD, RN,<sup>1</sup> Fawn A. Cothran, PhD, RN, GCNS-BC,<sup>1</sup> Kathryn E. Sexson, APRN, FNP-BC,<sup>1</sup> Diana J. Mason, PhD, RN, FAAN,<sup>2</sup> and Kathleen Buckwalter, PhD, RN, FAAN<sup>3</sup>

<sup>1</sup>Betty Irene Moore School of Nursing, University of California-Davis, Sacramento, California. <sup>2</sup>School of Nursing, George Washington University, Washington, DC. <sup>3</sup>Reynolds Center, College of Nursing, University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma.

\*Address correspondence to: Theresa A. Harvath, PhD, RN, FAAN, FGSA, Betty Irene Moore School of Nursing, University of California-Davis, Betty Irene Moore Hall, Suite 2400, 2570 48th St., Sacramento, CA 95817. E-mail: tharvath@ucdavis.edu

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## Abstract

The number of older adults living with functional decline and serious illness is growing exponentially at a time when availability of both family and professional caregivers is strained. Achieving optimal outcomes for this vulnerable population involves advancing the knowledge needed to improve the quality of care delivered by families, health professionals, and community programs. Recent reports from National Institute of Health and the National Academy of Science, Engineering and Medicine have called for the identification of gaps in key areas of family caregiving intervention research. In March 2018, the Family Caregiving Institute at UC Davis convened an invitational meeting of over 50 thought leaders in family caregiving—representing service agencies, funding organizations, and academia—to participate in the *Research Priorities in Caregiving Summit: Advancing Family-Centered Care across the Trajectory of Serious Illness*. Using an iterative process, attendees identified the top 10 research priorities and created research priority statements that incorporated a definition of the priority topic, rationale for the priority; problem(s) to address; priority population(s); and example research topics. The research priority statements serve as a roadmap for research development that will address the most significant gaps in the caregiving field.

Keywords: Caregiving-informal, Consensus, Diversity and ethnicity, Heterogeneity, Technology

The number of older adults living with chronic disease, functional decline, and serious illness is growing exponentially at a time when availability of both family and professional family caregivers is becoming strained. A tremendous amount of research has been conducted in the field of family caregiving, and we have made great strides in our understanding of this complex phenomenon. However, despite a large body of knowledge, there remains unanswered questions of how best to support the diverse needs of family caregivers who provide care to older adults with serious illness in the community (Schulz & Eden, 2016). Achieving optimal outcomes for this vulnerable population of older adults involves advancing the knowledge needed to improve the quality of care de-

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| Year | National report/summit  | Diversity | Heterogeneity | Trajectory | Technology |
|------|---|-----------|---------------|------------|------------|
| 2016 | <i>Families Caring for an Aging America</i> (Schulz & Eden, 2016). National Academy of Science, Engineering & Medicine <sup>a</sup>   | Х         | Х             | Х          | X          |
| 2016 | Report on Milestones for Care and Support Under the U.S.<br>National Plan to Address Alzheimer's Disease (Borson et al,<br>2016). Funded by the Alzheimer's Association.  | Х         |               |            | Х          |
| 2017 | <i>The Science of Caregiving</i> (National Institute of Nursing Research, 2017).  | Х         | Х             | Х          |            |
| 2017 | National Research Summit on Care, Services, and Supports<br>for Persons with Dementia and Their Caregivers (Gitlin &<br>Maslow, 2018). Report to the National Advisory Council on<br>AD Research, Care & Services. Funded by the U.S. Depart-<br>ment of Health & Human Services. | Х         | Х             | Х          | Х          |

Table 1. National Reports and Summits on Family Caregiving: Identified Priority Research Topics

Note: a Recommendation 1-g: Launch a multiagency research program sufficiently robust to evaluate caregiver interventions in real-world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes" (Schulz & Eden, 2016, p. 269).

livered by families, health professionals, and community programs.

In March 2018, the Family Caregiving Institute (FCI) at the Betty Irene Moore School of Nursing at the University of California Davis, convened a 2-day invitational summit titled, "Research Priorities in Caregiving Summit: Advancing Family-Centered Care across the Trajectory of Serious Illness." The vision of the FCI is (a) for families to be recognized for the role they play in health care delivery and (b) for consumers, health care professionals, and policy leaders to collaborate on developing evidence-based interventions, services, and community resources to address the diverse and complex needs of caregivers and their care recipients. To advance this vision, we invited over 50 family caregiving thought leaders to attend the summit, including researchers, policy advocates, funders from both public and private sectors and experts in caregiving services (see Supplementary Appendix for summit participants). The goal of the summit was to identify, define, and map research priorities to advance the field of caregiving intervention research, focusing within four broad domains already identified by national consensus (diversity, heterogeneity, trajectory, and technology). Key components of the summit included: presentation of briefing papers by four panelists; World Café style small-group discussions; synthesis of priorities and consensus activities; and development of priority statements and an action plan. This paper presents a description of the process used during the summit to identify priorities for intervention research, a summary of the priorities, and recommendations for developing a research agenda.

## Background: National Reports and Summits on Family Caregiving

In 1979, Ethel Shanas published a ground-breaking report debunking the myth that older adults in the United States were abandoned by their families (Shanas, 1979). Since then, thousands of research studies on the important social phenomenon of family care for older adults have been published. Still, important gaps in our understanding of how to address the complex issues faced by family caregivers for older adults remain. Notably, there have been several national reports or summits since 2016 that have focused on identifying gaps in addressing the needs of family caregivers (Table 1). The FCI faculty reviewed these documents to identify research topical areas with significant gaps.

In 2016, the National Academies of Sciences, Engineering, and Medicine (NASEM) published a report identifying the prevalence of family members caring for older relatives, the complex nature of caregiving, and a set of recommendations to better meet the needs of family caregivers (Schulz & Eden, 2016). This report is a call to action for public policy makers to transform our health care system to become more person-and family-centered and "make caregiving an integral part of the nation's collective responsibility for caring for its older adult population" (pg. 255). The report also suggested that key stakeholders guide, through consensus, future research on priority interventions for caregivers (Schulz & Eden, 2016, pg. 269). Recommendation 1-g calls for the establishment of a program of research to test interventions for family caregivers, focusing specifically on the needs of diverse family caregivers, how needs may differ with varied caregiving experiences (e.g., different conditions, different caregiving relationship types), and how the needs of caregivers evolve over the course of the caregiving trajectory. The report also encourages exploration into how technology can enhance caregiver access to effective interventions. The four priority areas identified in the report-diverse caregivers, heterogeneity in caregiving experience, the changing trajectory of caregiving, and the integration of technology-are quite broad in scope. As the report does not specify the most critical intervention research to advance first, we used these four priority areas

as the FCI summit framework for generating targeted caregiving intervention research priorities.

In addition to the NASEM report, three other recent (i.e., since 2016) national reports and summits have focused on identifying research gaps in the needs of family caregivers. All of these reports/summits identified some combination of the same four priorities that were highlighted in the NASEM report (diversity, heterogeneity, trajectory, and technology), emphasizing their importance, but again without presenting specific insights into the critical first steps needed to advance each (see Table 1):

- The Alzheimer's Association National Plan Care and Support Milestone Workgroup published a report recommending key milestones to gauge the achievement of progress in the development of research to support individuals with Alzheimer's disease and their family caregivers (Borson et al, 2016). The research recommendations emphasized the need to address the unique needs of caregivers from diverse and underrepresented communities and the role of innovative technology in supporting family caregivers.
- The National Institute for Nursing Research (NINR) sponsored a summit on *The Science of Caregiving* (National Institute of Nursing Research, 2017). This 2-day meeting highlighted important issues and challenges in family caregiving research and identified priorities for future research, including the needs of multicultural family caregivers, the importance of leveraging technology to support family caregivers, and the changing needs of caregivers over time.
- The U.S. Department of Health and Human Services sponsored a 2-day summit in October 2017 titled National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers. The purpose of this summit was to set the national research agenda for care and services designed to support persons with dementia and their family caregivers (Gitlin & Maslow, 2018). The summit engaged stakeholders in a variety of activities that resulted in the identification of 12 themes to guide future research priorities. Included among the 12 themes was an emphasis on understanding the heterogeneity of family caregiving and how differences among and between family caregivers influences their experiences and needs for support, as well as the importance of the use of technology designed to support the specific needs of persons with dementia and their family caregivers.

## **Presentation of Briefing Papers**

Prior to the summit, the FCI commissioned briefing papers on the four broad priority research areas described above: (a) diverse needs of multicultural family caregivers; (b) heterogeneity of family caregiving; (c) trajectory of family caregiving; and (d) technology to support family caregivers (Table 2). We distributed the four briefing papers to the participants prior to the summit, and on the first morning of the summit each author presented a 10-min overview of key points. Participants were then invited to identify important gaps in the briefs and clarify seminal issues. These papers provided participants and facilitators with a platform for deeper discussions on each priority area throughout the summit. Next, we engaged in a series of activities to identify specific priority research topics for each broad priority area and to establish group consensus (Figure 1).

#### World Café Small-Group Discussions

Following the presentations, participants broke out into four groups—coinciding with the four broad priority research areas described above—for discussions in the style of a "World Café," a methodology designed to facilitate small-group dialogue within a larger group in order to uncover multiple perspectives on a common challenge (Brown & Isaacs, 2005). World Café has been implemented in both community and professional settings to leverage diverse perspectives and expertise in the development of strategic goals in the context of health (Rajaram, Grimm, Giroux, Peck, & Ramos, 2014; Sheridan, Adams-Eaton, Trimble, Renton, & Bertotti, 2010). Our goal for the World Café discussions was to

## **Table 2.** Briefing Paper Topics Used as Springboards to aList of Research Priorities

Multicultural Family Caregiving Historically, family caregivers from such populations as underrepresented minorities or members of the LGBTQ community have been largely ignored in caregiving research. Future studies must take into account these populations' unique experiences and examine additional necessary supports. Family Caregiving Across the Trajectory Most caregiving research has focused on the illness trajectory of the care recipient. But caregiving can also change over time: it may begin gradually or suddenly, or it can be episodic or chronic or a combination of these. Researchers must therefore examine interventions that would best support caregivers over time.

Heterogeneity in Family Caregiving Caregiving varies according to such factors as the care recipient's condition (e.g., dementia vs cancer), the caregiver's physical proximity to the care recipient, and geographic location (rural vs urban area). A better understanding of how these variables impact caregiving is needed.

Technology and Family Caregiving Technological innovations are rapidly accelerating. Research is needed to understand how to best use technology to support caregivers either through educational tools or as an adjunct to care.

Each briefing paper was in white paper form at the time of the summit. The paper on multicultural caregiving was adapted from Apesoa-Varano et al., 2015. The other three briefing papers were revised and submitted for publication in this special edition (Gallagher-Thompson et al.,; Lindeman et al.,; Young et al.).

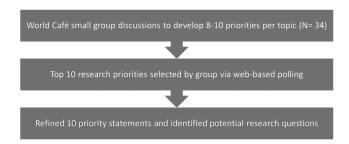


Figure 1. Consensus process.

generate a list of approximately 8–10 priority topics for each broad research area, along with supporting information explaining why each was a priority. Importantly, there is precedent for the World Café methodology in a conference setting to develop directions for research using participants with diverse disciplinary backgrounds and expertise (Haywood et al., 2015).

Participants rotated through three 30-min rounds of facilitator-led discussions, with the first two rounds preassigned based on the top two topics of interests they selected prior to the summit; we encouraged participants to select a different topic for the third round. During each round, they addressed two questions: What interventions or topics should be a priority for future research in this area? What contextual information will help us understand why this should be a priority? In the first round, participants were encouraged to generate a list of ideas that were "the most important" and to include "wild and crazy" ideas that may also have merit. In subsequent rounds, they reviewed the list generated from previous rounds and suggested ways to develop, combine, or delete topics to streamline the priorities. While the authors of the briefing papers were present to clarify information or answer questions, a separate facilitator led the discussion to avoid the emergence of preconceived priorities. Scribes recorded the discussions using a template document created for the World Café sessions; this evolving document was displayed on a large computer monitor so that all participants could view the growing list of priorities.

## **Consensus Process: Synthesis of Priority List**

In preparation for the next session, the facilitators, scribes, and authors collated the priorities (total n = 34) into lists of 8–10 items for their respective topics. We introduced the priority lists to the entire group in four online polls using Poll Everywhere software—a web-based audience-response system that allowed all participants to vote on their top five priorities for each of the four topics. Results were tabulated to create a list of 20 priorities, five from each of the four topic areas, which were inserted into a separate poll inviting participants to again select their top five priorities. As a result of this second poll, the group created a final list of 10 research priorities.

## Outcome: Development of Priority Statements

Participants worked in 10 small groups to develop one- to two-page "priority statements" using a template developed for this exercise that incorporated: a definition of the topic; rationale supporting the priority of the topic; problem(s) to address; priority population(s); and example research topics. A facilitator staffed each of the workstations and served as a scribe. At the start of this session, participants self-selected their first workstation and were encouraged to move to different workstations as the session progressed so that the final draft of priority statements reflected input from multiple perspectives. A "close to final" draft of the priority statements was generated by the end of the first day, through the collective efforts of the participants. That evening, FCI faculty edited the draft for clarity and readability (but not for substance) and shared the revised draft with all participants the following day. Following the summit, FCI faculty and staff continued to edit the list of research priorities and accompanying statements for clarity; a final version of the research priorities with the accompanying supporting documentation is available on the FCI website: https://health.ucdavis.edu/nursing/familycaregiving/pdfs/ Updated\_Research\_Priorities\_Jan2019.pdf. Refer to Table 3 for a summary of the research priorities, descriptions, and sample research questions. These priority topics reflect important gaps in our knowledge of effective interventions for family caregivers. It is interesting to note that even though the consensus process could have resulted in the elimination of one of the initial four designated broad priority areas (i.e., diversity, heterogeneity, trajectory, or technology), at least one specific research priority topic from each broad focus area made it into the final list. In fact, many of the priorities reflect a synthesis of two or more of the broader priority areas (e.g., research priority #2 combines both technology and the trajectory of caregiving).

## **Additional Outcomes**

Over the course of the summit, several other noteworthy topics emerged from the discussion, including terminology, the complexity of caregiving units, and underrepresented caregiving populations.

#### Terminology

Participants noted repeatedly that the term "family caregiver"—commonly used in the literature—can be problematic, as not all people who provide care are related to the care recipient by blood or marriage; neighbors, friends, or families of choice may also provide similar care and feel marginalized or excluded by the use of the term "family." Caregivers who are not related by blood or marriage to the care recipient may have unique needs that are not captured by our current body of research. Similarly, not all

changing needs of

giving.

family caregivers over

the trajectory of care-

jectory.

at the right time along the caregiving tra-

| Research Priorities  | Descriptions   | Sample Research Questions  |
|--|--|--|
| <ol> <li>Evaluate technologies<br/>that facilitate choice<br/>and shared deci-<br/>sion-making.</li> <li>Determine where<br/>technology is best<br/>integrated across the<br/>trajectory of care-<br/>giving.</li> </ol> | Design technology-enabled interventions<br>that facilitate choice and shared deci-<br>sion-making and examine the effects of<br>these interventions on care recipients,<br>family caregivers, and members of the<br>healthcare team.<br>Technology can support family caregiver<br>interventions, but needs to be adapt-<br>able to the dynamic and changing needs<br>of caregivers over time. Two areas offer<br>opportunities for exploration: (1) adaptable<br>technology platforms that translate general- | <ul> <li>What is the impact of choice and shared decision-making on caregivers' well-being and on their ability to provide care to a loved one?</li> <li>What type of access to information and specific capabilities can technology offer caregivers in order to facilitate shared decision-making? Does the impact of technology and access to information on shared decision-making vary according to geographic area (rural vs. urban) and socioeconomic status?</li> <li>How can everyday technologies such as smart phones, security devices, environmental control units, and smart speakers be deployed to support family caregivers?</li> <li>What safeguards or additional features might be necessary as these technologies are adapted?</li> </ul> |
|  | izable solutions to tailored interventions;<br>and (2) algorithms that match technologies<br>with caregiving needs across time.  |  |
| 3. Evaluate family-<br>centered adap-<br>tive interventions<br>across conditions,<br>situations, stages,<br>needs, preferences,<br>and resources.  | Research is needed to address the diver-<br>sity and heterogeneity of family caregiving<br>according to the care recipient's illness and<br>the severity of his or her condition; culture;<br>religion; gender; race/ethnicity; sexual orien-<br>tation; family composition; setting; and socio-<br>economic status. Such research should involve<br>families in the design, consider optimal timing<br>for interventions, and reflect caregivers'<br>strengths, vulnerabilities, and preferences.             | <ul> <li>How do the preferences and needs of diverse families and family caregivers impact the efficacy of interventions across the caregiving trajectory?</li> <li>How do changes in care recipients and their families interact to affect the physical and emotional well-being of all family members, across diverse populations?</li> </ul>  |
| 4. Examine the<br>heterogeneity of<br>attitudes, values and<br>preferences toward<br>caregiving, services<br>and supports  | Research must focus on strategies to iden-<br>tify, assess, and support the unique and<br>varied needs of families who provide care,<br>and assess the subjective experiences of<br>caregivers, including their attitudes, values,<br>preferences, feelings, and expectations.   | <ul> <li>What cross-culturally valid, comprehensive assessment tools and methods can be developed, tested, and implemented to elicit caregivers' subjective experiences, including their willingness to assume the role of caregiver, their attitudes toward different aspects of the role (for example, personal care versus emotional support), their values and preferences regarding goals and shared decision-making, and their needs for services, training, and support?</li> <li>What best practices for assessment of caregivers along the caregiving trajectory can be developed, tested, and implemented? What is the best timing and frequency of assessment of caregivers' attitudes, willingness, and readiness for the role?</li> </ul>         |
| world complexity,<br>translation, scalability,   |  | <ul> <li>What are the desired outcomes for family caregiver interventions at individual, family, health system, and community levels?</li> <li>What domains (e.g., jobs/wages, family functioning, ethical considerations, role choice, or task complexity) should be included in outcome assessments?</li> </ul>  |
| <ul> <li>and sustainability.</li> <li>6. Develop a conceptual framework and typology of the trajectory of caregiving for new interventions and outcomes.</li> </ul>  | bility and sustainability.<br>There is a need for a comprehensive family<br>caregiving framework or typology that reflects:<br>developmental phases; contextual factors; the<br>dynamic, reciprocal and interdependent nature<br>of the family caregiver-care receiver interface<br>and interactions; and the complexities at var-<br>ious timeframes along the trajectory.  | <ul> <li>What is the business case for promising caregiver interventions?</li> <li>What domains and factors comprise the conceptual framework<br/>and typology of the caregiving trajectory?</li> <li>How can a conceptual framework and typology of the care-<br/>giving trajectory be used to inform and guide development of new<br/>interventions?</li> </ul>  |
| 7. Conduct risk/needs assessment of the  | The changing needs of caregivers over time call for the right interventions provided   | • What are the internal/external factors that influence the family caregiver beyond direct caregiving?   |

| Table 3. | Research | Priorities, | Descriptions, | and Samp | ole Research Q | Duestions |
|----------|----------|-------------|---------------|----------|----------------|-----------|
|          |          |             |               |          |                |           |

• What are the health, economic, and social variables associated with increased risk to family caregiving situations over time?

| <b>Research Priorities</b>   | Descriptions   | Sample Research Questions  |
|--|--|--|
| 8. Conduct implemen-<br>tation research on<br>evidence-based care-<br>giving programs for<br>diverse populations.          | As the older adult population becomes more<br>ethnically and culturally diverse, there is an<br>acute need to examine existing intervention<br>models and their suitability and effective-<br>ness for diverse populations. This calls for<br>theoretically-driven research that accounts for<br>community- and individual-level variables, and<br>identifies if, how, and for whom interventions<br>should be adapted, and in what situations new<br>interventions must be developed? | <ul> <li>What formative research methods are most effective in deciding when an evidence-based intervention can be adapted for a specific population and when a new approach needs to be developed?</li> <li>What are the optimal strategies for identifying the adaptations to interventions necessary for diverse populations?</li> </ul>  |
| 9. Develop outcome<br>measures that are<br>relevant to family<br>caregivers from<br>diverse social and<br>cultural groups. | This priority calls for foundational re-<br>search to develop new measures and meth-<br>odological studies designed to evaluate<br>existing measures for diverse populations<br>and adapt them as needed.  | <ul> <li>How do we know that a potential intervention worked from the perspective of caregivers from diverse backgrounds?</li> <li>What constitutes a meaningful outcome from the perspective of diverse caregivers?</li> </ul>  |
| <b>10.</b> Develop research<br>methodologies that<br>account for the com-<br>plex structures of<br>family caregiving.      | Research must account for differences in<br>how individuals providing care to an older<br>adult define "family" and for situations<br>where more than one person is providing<br>care.   | <ul> <li>How do the divergent configurations of families affect outcomes?<br/>How do these caregivers communicate healthcare information to<br/>each other?</li> <li>What interventions would help educate healthcare providers about<br/>culturally-based definitions of family, and how would clinicians' grasp of<br/>these definitions affect outcomes for both care recipients and caregivers?</li> </ul> |

#### Table 3. Continued

who engage in family caregiving identify as "caregivers." Instead, they see themselves as simply enacting the role of relative, neighbor, or friend. In addition, studies currently use diverging operational definitions of "caregiver," challenging the consistent identification of who is a caregiver and who is not, and comparisons and generalizations of findings across studies.

#### Complexity of Caregiving Units

Several participants commented on the limits of existing measures and analytic methods to capture the complexity of family caregiving over time. Most research assumes a static dyad composed of one care recipient and a single caregiver. We know that often multiple caregivers are involved, that caregivers change over time, and that designations of care recipient and caregiver within a dyad can switch back and forth, especially between aged spouses. Future research should include new methods to capture the complexity of family caregiving and the evolution of family caregiving over time.

#### Underrepresented Caregiving Populations

Participants emphasized the importance of new methods and strategies to better identify and include caregivers who are historically underrepresented or otherwise marginalized. As discussed in the summit paper focused on complex caregiving trajectories (Gallagher-Thompson et al., 2020), at-risk caregivers (e.g., financially vulnerable

at baseline or because of caregiving) may not be able to participate in research or interventions due to limited health care access or resources (e.g., transportation), and culturally underrepresented minorities may be hesitant, unable to participate, or excluded (e.g., language). Importantly, as discussed in our summit paper on heterogeneity (Young et al., 2020), frequently cited systematic reviews and meta-analyses of caregiving interventions often treat study populations as homogeneous, which masks (and can serve to perpetuate) economic and racial disparities in caregiving research. This is particularly concerning given that certain subgroups of caregivers experience negative physical and mental health effects of caregiving more strongly than others (Bom, Bakx, Schut, & Van Doorslaer, 2019). Therefore, in addition to developing new intervention strategies, future research should address marginalization at the conceptual level (e.g., Research Priority #6) to better understand and measure the critical contextual factors that impact caregivers and care recipients (e.g., culture, financial resources, health literacy). Moreover, intervention strategies that are already supported by evidence should be applied and adapted to caregiving contexts where they may be most needed at the implementation level (e.g., Research Priority #8).

## Vetting and Dissemination

Following the identification of research priorities, the FCI faculty developed a plan to help move this research agenda forward using key stakeholder reaction panels,

development of an action plan, and vetting with a wider audience of experts in family caregiving.

## **Reaction Panels**

On the second day of the summit, two panels provided comments about the research priorities. The first panel was composed of experts in the field of aging services (Kathy Kelly, Robyn Stone, and Donna Yee; see Supplementary Appendix for affiliations). The second panel was composed of representatives from philanthropic and federal organizations that provide funding for research and services focused on aging and caregiving (Melissa Gerald, Karen Huss, and Diana Schweitzer; see Supplementary Appendix for affiliations). Each panel responded to three questions:

- What is your reaction to these priority areas? What do you think the impact would be for caregivers if this research were carried out?
- Is there anything missing from this list? Are there elements that you think might be a lesser priority?
- Please describe how these priorities fit within your organizations' understanding of the field and the priorities of the people they serve.

The panelists supported the priorities and identified additional issues for consideration, such as: barriers to caregivers participating in research; family caregiving as unpaid labor and the return on investment gained from supporting caregivers; and common data elements that support examining commonalities across studies. Following reactions from each panel, participants were invited to join the conversations and to offer additional comments on the relevance of the 10 priorities for research. The outcomes from these two reaction panels and subsequent participant discussions served as the foundation for the development of an action plan in the next session.

#### Development of an Action Plan

The summit concluded with participants identifying further steps to help advance the research priorities. Several themes emerged from discussions throughout the 2-day summit. In line with the rapidly growing body of research concerning technology and aging (Pruchno, 2019), participants stressed the need to evaluate technologies that facilitate care recipient and caregiver choices and shared decision making, and to determine best practices for integration of technology across the trajectory of caregiving. As discussed in the technology-focused summit paper (Lindeman et al., 2020), technology holds great promise for supporting caregivers and care recipients. Namely, technology can be used to: enhance access to crucial information, education, and training for caregivers; improve care management and decision support using advanced analytics; serve as a vehicle for social support/social isolation interventions, particularly

for caregivers who are geographically isolated; support caregivers in the home with remote monitoring and telemedicine; and mitigate some of the practical challenges of care recipient transportation (e.g., to appointments, pharmacy).

Moreover, the group recommended development of a risk/needs assessment to identify the evolving circumstances of family caregivers over time, and interventions that consider factors such as the care recipient's condition and stage of illness, and the caregiver's life situation and evolving needs. Finally, they encouraged an examination of the heterogeneity of attitudes, values, and preferences regarding caregiving and supportive services, and stressed the importance of multicultural factors affecting caregiving. All agreed that research needs to be conducted with diverse populations, and the methodologies used in future studies should take into consideration the complex structures of family caregiving. The summit concluded with participants completing commitment forms to indicate the activities they would be willing to tackle and recommended actions that should be pursued by the FCI.

# Vetting with a Wider Audience of Family Caregiving Experts

The FCI sponsored a *Pre-Conference Workshop on Research Priorities in Caregiving* session at the 2018 Gerontological Society of America (GSA) Annual Scientific Meeting. Fiftyfour individuals from academia, as well as from clinical, policy, and aging services, attended the session. The purpose of the workshop was to review the summit findings and research priorities, discuss methodological issues in caregiving research, and promote partnerships to stimulate research.

Feedback reflected support for researchers to collaborate on generating larger datasets, discovering new ways to use electronic health records within caregiving research, and designing larger, multisite caregiving studies. Moreover, numerous participants reiterated the concerns already stressed at the summit—that the term "family caregiver" can be a roadblock in both caregiving research and service delivery, as many people who provide this type of care are not related by blood or marriage, nor do they self-identify as caregivers.

## Conclusion

Within the past 5 years, advancing research to better support the needs of family caregivers has become an area of increasing emphasis at both federal and foundation levels. Several recent, high-profile national summits and consensus reports have put forward research recommendations for family caregiving. This paper reports the process and outcomes of the Family Caregiving Institute's *Research Priorities in Family Caregiving Summit* held in spring 2018. The goal of the summit was to identify targeted, intervention-specific research priorities within a framework that reflects four broad research gap areas already identified across recent national reports and summits (diversity, heterogeneity, trajectory, technology). We invited nationally recognized scientists, policy advocates, funders, and representatives from caregiver services and community organizations, and engaged their expertise in a consensus-building process (the World Café method) over 2 days. We convened a preconference session at the 2018 GSA Annual Scientific Meeting to discuss the summit outcomes presented in this paper (10 intervention research priorities for family caregiving) and gain feedback from a wider public audience. Developing targeted research priorities within nationally identified, broader gaps using expert consensus leverages decades of realworld research and community experience. The research priority statements are intended to serve as a roadmap for research development that will address the most significant gaps in the caregiving field. We hope the collective experience and effort reflected in these summit priorities will support caregiving researchers and research sponsors as they make difficult decisions about which specific research areas may be most impactful to address first-both in terms of meeting the most urgent needs for caregivers, providers, and policymakers, and in terms of building a strong foundation for developing, testing, implementing, and scaling interventions that meet the diverse and complex needs of family caregivers over time.

## **Supplementary Data**

Supplementary data are available at The Gerontologist online.

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## **Conflict of Interest**

None reported.

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