



Research Priorities in Caregiving:

Advancing Family-Centered Care
across the Trajectory of Serious
Illness

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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 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. The Family Caregiving Institute at the Betty Irene Moore School of Nursing at UC Davis brought together more than 50 thought leaders at the two-day *Research Priorities in Caregiving Summit: Advancing Family-Centered Care across the Trajectory of Serious Illness* in March 2018 to identify, define and map out research priorities to advance the caregiving field. Summit participants identified priorities and developed an action agenda that emphasizes interventions that incorporate multicultural approaches and the use of technology to optimize care for a person with serious illness.

A diverse group of participants from numerous fields participated in the discussion, including individuals representing service agencies, funding organizations, and academia. Four briefing papers developed in preparation for the summit aided in discussions related to: *Trajectory of Family Caregiving; Technology in Caregiving; Multicultural Caregiving; and Heterogeneity of Family Caregiving*. Following a brief review of the opportunities and challenges within these topics, participants rotated through a series of small-group discussions to identify research priority areas. Using a web-based audience-response program, the group then identified the top research priority areas (Table 1), which were expanded upon to include problem(s) to address, a description of the topic area, priority population(s), rationale as a priority topic, and potential research questions.

Table 1: Caregiving Research Priority Statements

Caregiving Research Priorities	
A	Evaluate technologies that facilitate choice and shared decision-making.
B	Determine where technology is best integrated across the trajectory of caregiving.
C	Evaluate family-centered adaptive interventions across conditions, situations, stages, needs, preferences and resources.
D	Examine the heterogeneity of attitudes, values and preferences toward caregiving, services and supports.
E	Evaluate family caregiver interventions in ways that address real world complexity, translation, scalability and sustainability.
F	Develop a conceptual framework and typology of the trajectory of caregiving for novel interventions and outcomes.
G	Conduct risk/needs assessment of the changing needs of family caregivers over the trajectory of caregiving.
H	Conduct implementation research on evidence-based caregiving programs for diverse populations.
I	Develop outcome measures that are relevant to family caregivers from diverse social and cultural groups.
J	Develop research methodologies that account for the complex structures of informal caregiving.

On the second day of the summit, representatives from funding agencies and service agencies shared their perspectives on and reactions to the draft research priorities statements, as well as participated in discussions with the group on how the priorities can best advance the field.

Research Action Agenda

The final session focused on identifying an action agenda to improve the lives of the more than 40 million Americans who provide unpaid care across the country. This action agenda serves as a blueprint for the design, implementation and evaluation of research projects to improve the health and well-being of caregivers.

Funded through a grant from the Gordon and Betty Moore Foundation, the goal of the Family Caregiving Institute is to advance research, education and policy to support caregivers in the demands that impact their mental, physical and financial health, as well as threaten their quality of life.

Research Priorities in Caregiving

Title	A. Evaluate technologies that facilitate choice and shared decision-making.
Problem(s) to be Addressed	Technologies that support health encompass a broad landscape of mobile applications, computer programs, devices, analytical tools, and decision-support systems for care recipients and their family caregivers. Not all those who could benefit from technology-enabled solutions and data-informed decision-making are able to do so because of cost, access or knowledge.
Description of Priority Topic Area	This research priority focuses on the design of technology-enabled interventions that facilitate choice and shared decision-making that examines the perspectives of, and impact on, care recipients, family caregivers, and members of the healthcare team.
Priority Population(s)	All caregivers, especially those who are under-resourced and under-represented in research and experience disparities in technology access and use (e.g., low income and rural families).
Rationale for Priority	Technology can bridge gaps among stakeholder groups and their sometimes competing priorities. Technology can empower family caregivers to play active roles in healthcare decision-making.
Example Research Questions	<ul style="list-style-type: none"> • What is the impact of choice and shared decision-making on caregiver outcomes and caregivers' ability to affect care recipient outcomes? • What information access and specific capabilities does technology provide caregivers in 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? • How can existing shared decision-making frameworks/models be adapted to accessible, low-cost technology-enabled interventions? • Does access to/use of the EHR by caregivers and care recipients improve decision-making or outcomes (psychosocial, physical, spiritual, clinical, care coordination)? • What data should be integrated into the EHR (e.g., from mobile/sensor/wearable devices/ambient monitors) to support shared decision-making and informed choice? • How can complex health information be delivered to support shared decision-making? • How can rich qualitative data (e.g., notes, observations, reports) be incorporated into decision-making in replicable/scalable/efficient ways? • What research methods can successfully be applied to the technology innovation cycle (participatory, user-centered, co-design), with special attention to inclusion of caregivers under-represented in research? • What measures of technology acceptance and effectiveness are relevant for shared decision-making with family caregivers, especially within under-resourced and under-represented populations?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Funding and other support for: <ul style="list-style-type: none"> ○ Engaged interdisciplinary collaboration among designers, health researchers, participants; and ○ Development and use of methodologies that are alternatives to RCT/pragmatic trials given rapid turnover in technology innovation cycles. • A compendium of successful technologies and methodologies, including those tested with low-income and rural families, to encourage enhancement/adoption of successful strategies.

Title	B. Determine where technology is best integrated across the trajectory of caregiving.
Problem(s) to be Addressed	Caregivers' needs, experiences, preparedness and capabilities change over the caregiving trajectory and vary by cultural context. Technology-enabled interventions rarely account for the unique and shifting needs of family caregivers (e.g. in terms of equity, access, technology receptivity, stage of caregiving, diversity of perspectives).
Description of Priority Topic Area	Two areas of exploration offer opportunities: (1) adaptable technology platforms that translate generalizable solutions to tailored interventions; and (2) algorithms that match technologies with caregiving needs across time.
Priority Population(s)	All family caregivers across the caregiving trajectory (e.g., early caregiving, mid-stage, complex conditions, end-of-life).
Rationale for Priority	Technology can support family caregiver interventions, but needs to be adaptable to dynamic and changing needs across the caregiving trajectory.
Example Research Questions	<ul style="list-style-type: none"> • How can everyday technologies (e.g., smart phones, security devices, environmental control units, smart speakers and related applications) be deployed to support family caregivers? • What safeguards or additional features might be needed as these technologies are adapted? • What are effective approaches to assuring that technologies employed do not quickly become obsolete? • How can frameworks for technology adoption, usefulness and usability be applied to family caregivers? • What are user perceptions of privacy, security, consent and ethical considerations in relation to social and networked technologies? What are the best practices for educating stakeholders about these issues? • What are the needs and use cases for technology-supported caregiving across the caregiving trajectory? • How can technology enable caregiver training, respite, and self-care? • How do caregivers' views of technology differ by generation and how does this affect development/implementation of technology solutions?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Foundational work to characterize and define trajectories of caregiving • Technology evaluation driven by the relevant needs • Interdisciplinary collaboration (e.g., scientists who work with older adults, technology innovators, intended intervention recipients)

Title	C. Evaluate family-centered adaptive interventions across conditions, situations, stages, needs, preferences and resources.
Problem(s) to be Addressed	Most research studies focus on a single caregiver and single disease state in cross-sectional Anglo, college-educated, female caregiver populations.
Description of Priority Topic Area	Research is needed to address the diversity and heterogeneity of family caregiving by illness condition and stage, culture, religion, gender, race/ethnicity, sexual orientation, family composition, setting and socio-economic status. Such research should involve families in the design and optimal timing of the interventions and reflect caregiver strengths, vulnerabilities and preferences.
Priority Population(s)	Diverse caregiver groups
Rationale for Priority	Family caregiving is complex; the definition of family varies with cultural beliefs and context; and the diverse needs of family caregivers are unlikely to be served by static interventions or “best practices” developed and tested in narrow populations and limited illness conditions.
Example Research Questions	<ul style="list-style-type: none"> • How do preferences and needs of diverse families and family caregivers impact the efficacy of caregiver interventions across the caregiving trajectory? • How do changes in care recipients and families interact to affect physical and emotional well-being of all members in the family across diverse populations? • What are the most effective approaches to enhance provider communication with diverse families across the caregiving trajectory? • Does the inclusion of family-created goals optimize or improve outcomes across the caregiving trajectory? • What family-based interventions are effective at critical transition points in the caregiving trajectory?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • New conceptual models that focus on dyadic- and family-level concepts and interventions and reflect the complexity of family caregiving • New methods to identify and characterize family caregiving roles, components and support structures and to conduct dyadic- and family-level analytics

Title	D. Examine the heterogeneity of attitudes, values and preferences toward caregiving, services and supports.
Problem(s) to be Addressed	Many family caregivers do not see themselves as caregivers, remain invisible to the healthcare team, or are reluctant to continue in the role. Caring for a family member with physical, mental or functional impairment takes a toll on caregiver health and well-being. Stigma from care recipient loss of function or illness-related behaviors, and resulting social isolation, may further affect attitudes toward caregiving.
Description of Priority Topic Area	This area of research focuses on strategies to identify, assess and support the unique and varied needs of families who provide care, including assessment of the subjective experience of caregiving (e.g., attitudes, values, preferences, feelings, expectations).
Priority Population(s)	All caregiver populations, with a focus on those at the early stage and at critical transitions in the caregiving trajectory
Rationale for Priority	The subjective experience of caregiving intersects with culture, generation, gender, and socioeconomic status. Current assessment tools rarely address the tensions between the expectation of caregiving on the part of providers and the full range of caregiver subjective experiences. There is a need for anticipatory guidance tailored to the individual caregiver for assuming the caregiving role and facing its challenges.
Example Research Questions	<ul style="list-style-type: none"> • What cross-culturally valid, comprehensive assessment tools and methods can be developed, tested and implemented to elicit caregiver subjective experiences, including willingness to assume the role, attitudes toward different aspects of the role (e.g. personal care versus emotional support), values and preferences for care goals and shared decision-making, as well as needs for services, training and support? • What supports cultivate caregiver resilience? • What best practices for caregiver assessment along the caregiving trajectory can be developed, tested and implemented? What is the best timing and frequency of assessment of attitudes, willingness and readiness for the role and change in assessment focus? • What assessment tools for family and care team mapping can be developed, tested and implemented to account for relationship quality and complexity? • What are the antecedents and risk factors associated with caregiver subjective experiences, caregiving quality or sustainability, including social determinants and financial health (e.g., burden, security)? • What are best practices to support caregivers as they exit or opt not to continue in the caregiving role?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • New approaches to engage diverse communities in family caregiving and caregiving research and elicit the range of subjective experiences. • Foundational work that is specific to the language of caregiving, including identifying appropriate terms for family caregiving that are acceptable and understandable to priority populations.

Title	E. Evaluate family caregiver interventions in ways that address real world complexity, translation, scalability and sustainability.
Problem(s) to be Addressed	Existing research and funding mechanisms in family caregiving tend to have narrow criteria, approaches and Priority Populations; inadequately address the “real world” complexity of the role; do not always address the complexity of needs (e.g., health, spiritual, social, tangible/financial, education); and do not always support meaningful stakeholder engagement.
Description of Priority Topic Area	There is an urgent need for intervention research to accelerate translation of promising family caregiving interventions to practice, to adapt such interventions to meet the needs of diverse communities, and to assure future scalability and sustainability.
Priority Population(s)	All family caregivers, particularly those from diverse social and cultural groups
Rationale for Priority	The sustainability of family caregiver interventions depends on their being embedded in real world delivery systems including clinical, community and virtual settings.
Example Research Questions	<ul style="list-style-type: none"> • What are the desired outcomes for family caregiver interventions at individual, family, health system, and community levels? • What are the domains that should be included in outcome assessments (e.g., health, jobs/wages, education, family functioning, ethical considerations, role choice, task complexity)? • What are the indicators of financially sustainable and scalable caregiver programs and interventions? • What is the business case for promising caregiver interventions? • What are optimal payment structures and models that support the diverse needs of family caregivers (e.g., tax credits, stipends, workforce retraining after caregiving role)? • What best practices for adaptation and widespread adoption of promising interventions across diverse communities can be developed, tested and implemented?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Innovative, multidisciplinary research approaches and methodologies that demonstrate efficiency, value, scalability and sustainability of promising interventions. • Strategies to prioritize approaches or interventions that should be scaled and sustained • New funding resources for: (1) stakeholder engagement in intervention design, adaptation, testing and dissemination; (2) capacity building among community-based organizations where interventions will be tested or launched; and (3) meaningful long-term partnerships with stakeholders

Title	F. Develop a conceptual framework and typology of the trajectory of caregiving for novel interventions and outcomes.
Problem(s) to be Addressed	Most family caregiving theories are individual or dyadic, rather than family-centered and context-focused. Most were developed without consideration of factors such as life expectancy, co-morbidities, multi-generational caregiving, diverse populations, technology, and globalization. Consequently, researchers do not have access to a comprehensive family-centered caregiving framework/typology, thus limiting: (1) their ability to consider the complexity of context and trajectory; and (2) comparability of interventions and outcomes across the trajectory.
Description of Priority Topic Area	There is a need for a comprehensive family caregiving framework or typology that reflects: developmental phases; contextual factors; the dynamic, reciprocal and interdependent nature of the family caregiver-care receiver interface and interactions; and the complexities at various timeframes along the trajectory.
Priority Population(s)	All caregivers
Rationale for Priority	A comprehensive family caregiving framework/typology offers the opportunity to define and operationalize the dynamic and evolving nature of family caregiving over time, serving as a guide to the development of novel interventions and their delivery that consider the complexity and individual context of family caregiving and timing.
Example Research Questions	<ul style="list-style-type: none"> • What are the domains and factors that comprise the conceptual framework and typology of caregiving trajectory? • How can a conceptual framework and typology of caregiving trajectory be used to inform and guide development of novel interventions/ outcomes? • What are the common caregiver trajectories and variations in trajectories based on evolving needs of the care recipient? • How does caregiving evolve over time, including how caregivers work together? • What are important outcomes to measure across different stages of the caregiving trajectory? • What best practices in assessing family caregiver knowledge, skills, and abilities can be developed, tested and implemented?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • There is a need for a synthesis of literature and existing frameworks to inform the development of a comprehensive family caregiving framework/typology.

Title	G. Conduct risk/needs assessment of the changing needs of family caregivers over the trajectory of caregiving.
Problem(s) to be Addressed	Very little is understood about: (1) the evolving needs of family caregivers over time; (2) critical periods along the caregiving trajectory when comprehensive or focused assessment should be conducted in order to identify families/caregivers at risk for negative outcomes or breakdown in care; and (3) variables (e.g., family caregiver vs. care recipient vs. family) most important to monitor over time in order to prevent or ameliorate risk.
Description of Priority Topic Area	This priority topic focuses on the changing needs of families/caregivers over time to target the right interventions for the right time in the caregiving trajectory.
Priority Population(s)	All family caregivers
Rationale for Priority	Family caregiver situations are dynamic and change over time. Outcomes may be improved by identifying risk factors and critical points along the caregiving trajectory.
Example Research Questions	<ul style="list-style-type: none"> • What are the internal/external factors that influence the family caregiver outside of the direct caregiving? • What are the health, economic, and social variables associated with increased risk? • Do changes in family caregiver risk/needs change in ways that are related to other factors (e.g., disease processes)? • What are the definitions of outcomes that are sensitive to changes in caregiving over time, including definition of outcomes as reported by caregivers vs. external measures/standards? • What are best practices in identifying known shifts in family caregiving and how are these shifts defined? How do family caregivers describe important shifts in the caregiving trajectory? • What are best practices in predicting which family caregivers are at risk and need more support? • How can a focus on wellness and prevention help with early identification of an imminent need for caregiver support?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Literature synthesis on: <ul style="list-style-type: none"> ○ Standard assessments currently available and in use; ○ What is known about the complexity of family structures; ○ How people experience the care they provide; their motivations, rewards, and expectation; ○ The nature of the relationship in their own words; ○ The role of reciprocal exchange; and ○ The influence on the relationship when the medical lens is applied. • Healthcare delivery systems need electronic health records that identify all family caregivers involved in the care of the recipient.

Title	H. Conduct implementation research on evidence-based caregiving programs for diverse populations.
Problem(s) to be Addressed	While a number of evidence-based treatments exist for caregivers of older adults living with chronic health conditions, most have been developed in predominantly white non-Hispanic population and their efficacy has not been tested in diverse populations. Little is known about the nature and types of cultural adaptations necessary to optimize outcomes for diverse populations.
Description of Priority Topic Area	This priority topic area includes theoretically driven research that accounts for community and individual-level variables and identifies if, how, and for whom interventions need to be adapted and new interventions developed for diverse populations. As the older adult population becomes more ethnically and culturally diverse, there is an acute need to examine existing intervention models and their suitability and effectiveness for diverse populations, and to identify subgroups for which novel interventions may need to be developed.
Priority Population(s)	Culturally diverse populations currently under-represented in caregiver intervention research.
Rationale for Priority	Before “scaling-up” available interventions, we need to make sure they are effective across different segments of our population. In addition, interventions need testing in real-world clinical and community settings with attention to sustainability.
Example Research Questions	<ul style="list-style-type: none"> • What formative research methods are most effective and efficient in making decisions about whether an EBT can be adapted for a specific population or if a new approach needs to be developed? • What are the optimal strategies for identifying the adaptations to interventions that are necessary for diverse populations? • How can key stakeholder groups (e.g., family caregivers, care recipients, providers, administrators) be engaged in the intervention adaptation process? • What are the theoretical models that can be used to inform the cultural adaptation process? • Are culturally adapted models more cost-effective and sustainable compared with non-adapted interventions?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Multi- or single-site pragmatic trials powered to examine the effectiveness of interventions with multiple diverse populations and guided by existing theoretical frameworks. • Support for the development of formative interventions with populations that are particularly difficult to reach or engage and may benefit from novel approaches.

Title	I. Develop outcome measures that are relevant to family caregivers from diverse social and cultural groups.
Problem(s) to be Addressed	Most outcome measures used to evaluate caregiving interventions have been developed in heterosexual, Caucasian caregiver samples. Few outcome measures have been developed and normed in diverse groups making it difficult to discern the meaningful impact of interventions for these caregivers.
Description of Priority Topic Area	Recognizing the need for development of outcome measures focused on the specific and unique needs of family caregivers from diverse social and cultural groups, this research priority involves foundational research to develop new measures and methodological studies designed to adapt and evaluate existing measures in diverse populations.
Priority Population(s)	Historically marginalized caregiver groups based on social class, race, ethnicity, gender, sexual orientation, age, immigration status, religious backgrounds, and other characteristics.
Rationale for Priority	Systematic work that focuses on development of meaningful and sensitive measures that are responsive to stakeholder input and social context is needed to develop precise estimates of the effects of interventions. Identifying what constitutes “successful outcomes” requires an understanding of the views and experiences of diverse caregivers and their families/communities.
Example Research Questions	<ul style="list-style-type: none"> • How do we know that a potential intervention worked from the perspective of the caregivers from diverse backgrounds? • What constitutes a meaningful outcome from the perspective of diverse caregivers? • Is a particular instrument capturing an important outcome for a specific population/subpopulation? Is it reliable, valid, and sensitive to change? • What are individual preferences and group patterns? How do these intersect or not?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Involvement of key stakeholders, community members, leaders from the different communities of family caregivers in research. • Interdisciplinary teams in terms of content and methods, including experience of psychometric expertise. • Support for foundational work including participant compensation. • Community-based participatory research. • Multidisciplinary and multi-method teams. • Population-level research with nested n=1 studies or embedded case studies.

Title	J. Develop research methodologies that account for the complex structures of family caregiving.
Problem(s) to be Addressed	The structure of family caregiving is often complex, involving interdependent teams of caregivers who may work simultaneously or in succession; not related by blood or marriage; have physical and/or cognitive impairment; and change membership over time and situation. Dominant research methods do not readily capture this complexity and may miss effects of all relationships on outcomes and the impact of changes in caregiving composition over time.
Description of Priority Topic Area	There is a need for research to account for differences in how family is defined by individuals involved in providing informal care and for situations where more than one person is providing care.
Priority Population(s)	All caregivers, with an emphasis on groups/ cultures that embrace shared responsibility, shared decision-making and broad definitions of family.
Rationale for Priority	Demonstrating the effectiveness and impact of interventions requires assessment, measurement and methodologies that account for the complex nature of family caregiving structures; different perceptions of caregiving among those involved; and implications of these differences on disease/symptom management and outcomes.
Example Research Questions	<ul style="list-style-type: none"> • How do different configurations of family affect outcomes? How do these caregivers communicate healthcare information to each other? • What interventions are effective for educating providers about culturally-based definitions of family and how does the use of these definitions by clinicians affect care of recipients and caregivers? • What are bests practices to assess the incongruities in perceptions of symptoms among care recipients, caregivers and other family members? • What policy changes are needed to support diverse caregiving situations (e.g., employee policies, community, or reimbursement)? • What are the intended and unintended consequences of family caregiving policies on different family caregiving structures? • How can technology support diverse family caregivers and how can families be engaged in technology development to facilitate caregiving?
What is Needed to Move this Work Forward?	<ul style="list-style-type: none"> • Consensus on definitions and measures of family/community structures and composition; and common data elements for measuring family structure across different caregiving situations. • Application of network analyses to family caregiving to discern the variation in family care team composition. • Ethnographic and longitudinal interviewing across multiple groups involved in care to document dynamic social arrangements over time. • Cross-disciplinary work involving social scientists. • Adequate funding that recognizes the resource intensiveness of this research.

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