



The Science of Caregiving
Bringing **Voices** Together



A Summary

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National Institute
of Nursing Research

The Science of Caregiving: Bringing Voices Together – A Summary

On August 7 and 8, 2017, the National Institute of Nursing Research (NINR) and partners convened a trans-NIH Summit “The Science of Caregiving: Bringing Voices Together.” The summit brought together scientists, caregivers, advocates, providers, and health care professionals to learn about the issues and challenges facing caregivers and discuss the related research. Several NIH Institutes, Centers, and Offices partnered with NINR to make the summit possible:

- The National Cancer Institute
- The National Institute on Aging
- The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- The National Institute on Minority Health and Health Disparities
- The National Center for Advancing Translational Sciences’ Office of Rare Diseases Research
- The NIH Office of Behavioral and Social Science Research
- The NIH Office of Disease Prevention, and
- The NIH Office of Research on Women’s Health

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- American Association of Colleges of Nursing
- Oncology Nursing Society
- The Beckman Research Institute of City of Hope, Department of Population Sciences, Division of Nursing Research and Education;
- and The Honor Society of Nursing, Sigma Theta Tau International.

Opening and Keynote Addresses

NINR Director Dr. Patricia Grady opened the summit by introducing the topic of caregiving and described the increasing shift of health care responsibilities from formal health care providers and settings to individuals, families, and communities in managing chronic illness, noting there is growing evidence that the responsibilities of caring for family members and friends can have a significant negative impact on the health of caregivers, sometimes resulting in worse health for the care recipient. Dr. Grady highlighted NINR caregiver health research, including efforts to improve the quality of life for caregivers of patients with rare, advanced diseases, and self-management strategies to promote caregiver health.

In her keynote address, Judy Woodruff, anchor and managing editor of the PBS NewsHour, described her family's experience of being caregivers to her oldest son, born with spina bifida. The ongoing journey of caring for her son led to Ms. Woodruff's dedication to raising awareness of the critical role caregivers play in our society. In detailing her family's experience, Ms. Woodruff discussed the effect caregiving had on the family as a unit, as well as on each family member, and the need to remain positive and supportive. She recognized that her family was fortunate to have access to resources many others do not have and pointed out that as a nation, there needs to be better understanding of the role of caregivers, with much more work at both the federal and state level to raise awareness and expand support to caregivers.

The discussion that followed addressed best ways to prepare the next generation of health care professionals, with a focus on the importance of collaboration between the team members caring for an individual, especially in efforts to share medical information. Ideally, medical records would be contained in one place, accessible to all team members. Recalling her own experience, Ms. Woodruff cited a lack of guidance from health care providers. As a first step, health care professionals should be prepared

to have an initial discussion about the challenges faced with caregiving and provide materials and available resources during office visits.

Ms. C. Grace Whiting, CEO of the National Alliance for Caregiving and Director of Ceremonies for Day 1 of the symposium, offered that individuals and families could be partners in The Triple Aim, that was developed by Dr. Don Berwick, the former Centers for Medicare & Medicaid Services (CMS) administrator. The Triple Aim is a model for healthcare reform to achieve better health, lower costs, and better outcomes with better health care delivery, and Dr. Berwick noted the importance of family members in the healthcare process. Ms. Whiting described the essential role of family caregivers in helping with activities of daily living, finances, transportation, medical and nursing tasks, and advocating for the patient and serving as a liaison, often without adequate preparation. She added that family caregivers also improve the healthcare of populations, for example, reducing hospitalizations, which reduces costs.

Plenary 1: Issues and Challenges in Caregiving

The panel was moderated by Dr. Sara Douglas of Case Western Reserve University.

Mr. Mark Gibbons of the Caregiver Action Network (CAN) presented an overview of his non-profit organization, that provides education, peer support, and resources to family caregivers and works to improve the quality of life for Americans who care for loved ones. CAN catalogues websites targeted to specific caregivers and employers of caregivers. In addition to caregiver websites, Mr. Gibbons described a series of videos for caregivers of patients with Alzheimer's disease (AD), chronic obstructive pulmonary disorder, and Huntington's disease. Serving as peer-to-peer networks, the videos offer advice from family caregivers on topics including self-care, interacting with the care recipient, dealing with people outside the family, and finding caregiver support. Mr. Gibbons addressed what caregivers face, their daily challenges (transportation, medication management, meals, care management), the insufficiencies (money, time,

training, resources) and caregiver burnout (loneliness, depression, fear, anxiety). In closing, he noted that CAN is doing national outreach on shared decision-making, including evaluating comparative effectiveness research and querying physicians, and he emphasized that family caregivers need to be brought into the decision-making process early.

In her presentation, Ms. Christy Leonard of Debbie's Dream Foundation (DDF) focused on the challenges of caregiving from her own personal experience of being caregiver to her husband who has stage IV stomach cancer. She emphasized the importance of balance in the context of time for oneself, family, career, and relationships, noting that better self-care results in better caregiving. Planning for the future is also essential through open and honest conversation about the illness, Ms. Leonard noted, and does not mean that hope is lost. Instead, Ms. Leonard advises to be responsible early in the illness avoiding situations where it is too late to make legal decisions. She also described her work with the DDF that offers stomach cancer support services through the Patient Resource Education Program (PREP). She noted that, as an advocacy organization, DDF has hosted numerous Stomach Cancer Capitol Hill Advocacy Days and briefings resulting in federal research funding through the Department of Defense.

Ms. Mary Dunkle of the National Organization for Rare Disorders (NORD) addressed the challenges of caregiving through the lens of dealing with rare diseases. NORD is a federation of individual and patient organizations that provides programs of advocacy, education, patient and family services and research. Caregivers, Ms. Dunkle noted, are seeking connections, information, and support groups and resources. In addition to the physical, financial, time, and self-care challenges that have existed over the years, Ms. Dunkle described the unique factors of caregiving today including increasing numbers of identified rare diseases; enhanced diagnostic capabilities; increased emphasis on personalized medicine; social media for networking; and opportunities for global outreach. Ms. Dunkle stated that many caregivers express a sense of isolation and feelings of urgency, while at the same time, continue their learning to be an effective

partner within the health care team. Ms. Dunkle concluded her presentation by describing areas that need to be addressed to advance caregiving science: studies related to the caregiver's evolving role and the challenge of caregiving for the undiagnosed.

The discussion that followed Plenary 1 addressed existing gaps in caregiving research. Panelists stated that more must be done to include caregivers early enough in the process, designing interventions that include them, and increased emphasis on including both the care recipient and caregiver in patient-centered care. The importance of the caregiver's role in creating advance directives was also discussed, with panelists emphasizing that caregivers should ideally initiate these conversations to help draw out the care recipient to participate in such discussions. Discussion also turned to addressing the needs of those caregivers dealing with undiagnosed diseases, noting there is an added dimension of worry and anxiety for undiagnosed disease, that often falls on caregivers. The disconnect between primary care physicians and specialists was also noted in the discussion, with families finding it helpful to have the family physician be more involved with navigating the specialist care.

Plenary 2: Creating Change in Caregiving: Research to Policy

Ms. Kathleen Kelly of the Family Caregiver Alliance moderated the panel.

Dr. Sara Czaja of the University of Miami discussed technology initiatives to support family caregivers. She presented two research initiatives that use technology-based interventions for studying caregiving. The VideoCare intervention project evaluated the feasibility, acceptability, and efficacy of a video phone psychosocial intervention for family caregivers of AD patients. Included in the intervention were individual counseling sessions, video support groups, video educational seminars, annotated resource guide, caregiving tips, conferencing, and reminders. Dr. Czaja reported that caregivers participating in the intervention had a significant decrease in caregiving burden, and

significant increase in positive aspects of caregiving and social support. The second intervention, Caring for the Caregiver Network, was described by Dr. Czaja as a project to develop an effective intervention program that improves the quality of life of caregivers of AD patients, and enhances skills of and access to formal and informal support for caregivers. Progress on the intervention to date, showed that the available technology is acceptable, feasible, and beneficial to caregivers and care recipients. More research is needed on effectiveness and cost-effectiveness for diverse caregivers and care recipient populations.

Dr. Courtney Harold Van Houtven of Duke University examined how research can best inform policies to support caregiving in her panel presentation. She described the Program of Comprehensive Assistance for Family Caregivers (PCAFC) of eligible Veterans, a clinical program providing services directly to eligible caregivers. PCAFC participation increased access to care for veteran participants and showed promising trends towards reducing caregiver depressive symptoms and financial strain. Dr. Van Houtven suggested that research can best inform policies to support caregiving by embedding researchers in health systems and in operations and policy offices, and that partnered research can move toward a caregiver-friendly health system. As an example of how partnered research initiates health care delivery change that facilitates caregiver-friendly care, she touched on the Helping Invested Families Improve Experiences Study (HI-FIVES) skills training program for caregivers of veterans referred to home and community-based services. Dr. Van Houtven concluded that policies that achieve a caregiver-friendly health system better integrate caregivers into the healthcare team and increase training and support across clinical settings. In addition, she noted that there is a need for policies that increase long term services, supports choice and minimize negative economic consequences of caregiving.

Dr. Susan Reinhard of AARP gave an overview of the Home Alone study, published in 2012, that described the many complex medical-nursing tasks that family caregivers perform, that led to the Caregiver Advise, Record, Enable (CARE) Act, which supports

patients and family caregivers of all ages, and for any diagnosis, in 39 states. Currently, as discussed by Dr. Reinhard, AARP is conducting the National CARE Act Scan to evaluate implementation of the CARE Act. Dr. Reinhard concluded the presentation by noting that all of these activities are part of the Home Alone AllianceSM of public, private, and nonprofit sector organizations that are addressing what should be done to inform family caregivers of their responsibilities. The Alliance has developed as a first resource, videos from the focus point of the family caregiver.

The discussion after the second plenary session continued the conversation of how research can inform policy, as well as strategies to implement evidence-based policies. It was noted that reimbursement from insurance companies for care provided by family and friends is still an area requiring further exploration. Identification of caregivers in medical records is a challenge, due to systems policies in primary care settings, but the CARE Act is a vehicle for improving the practice in some hospitals. Disparities among racial and minority caregivers is still an area for research opportunity. Early engagement of community organizations was encouraged to obtain input and improve participation.

Day 1: Closing Remarks

Ms. Whiting highlighted key points of the afternoon, such as the importance of communication and attention to emotions and feelings. She noted that caregivers have a role in biomedical research, by taking responsibility for transporting patients to research clinics and monitoring medications, and that caregiver input and outcomes could be part of the drug development process.

Ms. Whiting emphasized the opportunities for using technology to support caregivers as well as the ongoing concerns about access to electronic medical records and sharing of information, how technologies can cross over and connect over the range of health care settings, what devices other than tablets and smart phones can be used, and how to improve the user experience. Ms. Whiting also echoed Dr. Van Houtven's advice to stop

waiting for the perfect idea and, instead, disseminate the best ideas more rapidly to move them forward.

Opening Remarks

Following a welcome and introduction by Dr. Grady, Dr. Laura Gitlin of The Johns Hopkins University and Director of Ceremonies for Day 2, identified additional contributors to caregiver health issues addressed by the summit. These included an aging society that requires more involvement of family caregivers, the growing gap between supply of and demand for family caregivers, and the increasing racial and ethnic diversity of families caring for relatives. Other trends have changed the dynamics of family caregiving, such as medical advances, shorter stays in hospitals and rehabilitation centers, the preference to remain at home and receive care there, and the expansion of home care technologies.

The focus of Day 2 of the Summit was: who needs care and who is providing care?

Plenary 3: Caregiving Research Focused on Children, Teens and Young Adults

Dr. Joanne Wolfe from the Dana-Farber Cancer Institute moderated this session and noted that parents of sick children live with uncertainty and are confronted with different caregiving challenges than caregivers of adults, for example: brain and physical development, schooling, and disparity in social support (e.g., cerebral palsy vs. cancer). Because chronic diseases are rare in children, there are fewer pediatric specialty clinics, creating geographic barriers, and difficulties in developing research cohorts.

Dr. J. Neil Henderson of the University of Minnesota addressed the behavioral strategies associated with mitigating parental distress in caring for children with type 1 diabetes. He described “diabetes by proxy,” resulting from parents trying to monitor a child’s condition. The specter of fatality in type I diabetes leads to parents’ constant vigilance, which increases the risk of burnout and excess stress. In addition, the trend of

new couples and new parents to distance themselves from the rest of the family compounds the burden of caregiving tasks for sick children.

Dr. Pamela Hinds from the Children's National Research Institute discussed her studies with seriously ill children that include end-of-life decision-making and their ability to self-report on treatment-related symptoms. She has surveyed parents to understand, what is "being a good parent to my seriously ill child?" The definition emerging from this research included: being knowledgeable about the medical condition for good decision-making; being the child's advocate with health care providers; remaining at child's side; providing basic care and teaching; and love. These data were used to develop a model for preventive self-care for parents of sick children.

Dr. Kathleen Baggett of Georgia State University addressed her research showing that home visit interventions can help parents to develop children's social interactions at an early age. She has also worked to improve the accessibility of caregiving practices for a wide range of caregivers, with an emphasis on the most vulnerable caregivers. For example, Baby-Net ePALS is a web-based program for parental coaching in child development that builds interaction skills and includes remote coaching support.

Comments resulting from the Plenary 3 discussion spanned many of the topics discussed in the presentations. Dr. Hinds's "good parent" model was viewed as a framework for developing decision-making in adult caregiving. "Diabetes-by-proxy" can be extrapolated to other pediatric diseases as well as adult conditions with potentially lethal outcomes, such as AD. These situations are wearying and stressful, but AD caregivers do not face the same imminent threats that interfere with sleep as in the case of caregivers of children with potentially lethal conditions or caregivers of heart failure or cancer patients. Coaching was a key factor in adherence to the home visit parenting intervention. The web-based distance coaching was effective and could be supported through local services. The shift of major caregiving responsibilities to family caregivers raises ethical, political, and economic concerns. In many cases, particularly with sick

children, family members are motivated and do not want to be displaced. However, there need to be more support systems, especially when individuals with chronic conditions and complex needs are living outside of health care facilities.

Plenary 4: Caregiving Research Focused on Acute, Serious Illnesses and Conditions

Dr. Kathi Mooney of the University of Utah moderated the panel and stated that caregivers need to be part of the health care system, and that new research questions need to challenge assumptions.

Dr. Frances Lewis of the University of Washington and Fred Hutchinson Cancer Research Center discussed her research on spouses of breast cancer patients, noting that early-stage disease was a major stressor, contributing to distress and depression even when the prognosis was good. Dr. Lewis identified predictors of depressed mood, such as pre-occupation at work, concern about the wife's death and their future as a couple, feeling excluded by the health care team, illness-related uncertainty, and life plans.

There was an assumption that spouses would rise to the challenge of their wives' breast cancer, but the study revealed that the men could not cope with the pressures of the illness and they felt that they failed in the role of protector. Tensions seemed to influence spousal pessimism of the marriage, which then affected household functioning.

Dr. Lewis and colleagues conducted a randomized controlled trial to evaluate a dyad communication intervention, Helping Her Heal, which addressed communication and depressed mood management. In comparison with the control group, the dyads receiving the intervention showed a trend towards reduced spouse anxiety and improvements in caregiver skills, communication skills, and patient outcomes.

In his presentation, Dr. Benjamin Levi of Penn State University mentioned that only 30% of individuals have completed advance directives. This leaves end-of-life decisions to others—decisions which frequently do not reflect the patient’s wishes. Dr. Levi and colleagues developed an online interactive tool for advance care planning (ACP) which simulates interaction with an informed professional and is designed to stimulate discussion. The tool includes videos about the implications of interventions and the conditions for which they are used, and it generates an advance directive document. The tool increased knowledge in end-of-life decisions, and facilitated discussion. In a small study of clinicians caring for amyotrophic lateral sclerosis (ALS) patients, the clinician’s use of the ACP tool improved the agreement between the clinical team’s treatment decisions and the patient’s end-of-life choices.

Dr. Levi and his colleagues assumed that caregivers would not be prepared to make surrogate decisions unless they completed the ACP tool with the patient, as a dyad. They tested a basic ACP tool in comparison with the educational, interactive ACP tool, completed individually or as a dyad. There was no difference in caregivers’ decision-making confidence or knowledge for those using the tools individually or as dyads. However, there was lower knowledge and higher confidence for those using the basic ACP tool and higher knowledge and lower confidence for those using the educational, interactive ACP tool.

The next speaker, Dr. Betty Ferrell of the City of Hope National Medical Center, cited a recent literature review of cancer caregiver research that showed a tremendous increase in studies in the past decade. However, most interventions required significant time commitments from caregivers.

Dr. Ferrell tested an intervention that assesses quality of life in a group of lung cancer patients and family caregivers. An interdisciplinary team conference was used to plan care and develop separate interventions for each patient and caregiver. The caregiver

interventions included instructions for caregiver self-care and patient care, and caregiver social well-being. The interventions also addressed both parties' psychological and spiritual well-being and instructions on ACP. The intervention yielded improvements in patient outcomes and caregiver distress, social and spiritual well-being for both, and longer survival for patients. Dr. Ferrell noted that patients and families need support through all stages of cancer, but the topics may change across the course of disease.

In the Plenary 4 discussion, Dr. Ferrell noted that most caregiving research is focused on dyads, particularly spouses, but that 30% of caregivers are not spouses. Particularly in low-income groups, caregivers are often children or grandchildren who must forgo education. She added that more research is needed to understand different concepts of caregiving in various cultural groups, but this can be challenging when caregivers are overwhelmed with full-time work and caregiving duties. Dr. Levi suggested that research that fulfills a need or evaluates something that caregivers do already could be more efficient.

Plenary 5: Caregiving Research Focused on Chronic Conditions/ Dementia/ Alterations in Cognition

Dr. Ralph Nitkin of the Eunice Kennedy Shriver National Institute of Child Health and Human Development moderated the session.

Dr. Debra Moser of the University of Kentucky addressed the impact of caregiving on physical health and mortality. Spousal caregivers experiencing caregiver strain are at increased risk for mortality; in the absence of stress, their mortality rates are similar to non-caregivers. Results from the Nurses' Health Study showed that caregivers with high levels (more than 9 hours per week) of caregiving responsibility had an 82% increased risk for coronary heart disease, in comparison with non-caregivers.

Dr. Moser has conducted caregiver research in the context of rural-urban health disparities, with a focus on Appalachia, an area with some of the country's lowest life expectancy figures.

Dr. Moser assessed a group of caregivers in the region, as well as non-caregivers, with an ill family member. She found higher depression, obesity, triglyceride levels, and hypertension rates in caregivers in comparison with non-caregivers. Non-caregivers with ill family members had lower levels of these measures than caregivers, but higher levels than non-caregivers without ill family members. Lifestyle interventions had the greatest impact on reducing depression in caregivers, indicating that caregivers had greater needs for health care, because they are often living in silence and isolation.

There are several interventions to improve caregiver competency and provide psychoeducational support but no interventions that target caregivers' cardiovascular health. Dr. Moser's current research aims to develop an intervention to address this gap, by looking at the impact of self-management behaviors on cardiovascular disease and depressive symptoms. She cited the need for longitudinal studies on the impact of poor caregiver health on care recipient and family outcomes, as well as statistical tools to analyze interaction of caregivers and health outcomes.

The next speaker, Dr. Jennifer Wolfe of The Johns Hopkins University described characteristics of caregivers who assist older adults with health care activities. Of nearly 15 million individuals, one-quarter felt an impact on their own health and one-half helped dementia patients. These caregivers were twice as likely to face physical, emotional, or financial impact or miss social events, and they were three times more likely to feel an impact on employment. These profiles can identify at-risk caregivers.

Family caregivers are critical in dementia care, for direct care as well as liaison with health care providers, which can sometimes put them in adversarial positions. Dr. Wolfe listed opportunities for more effective engagement of caregivers in care delivery, such

as: including caregivers in face-to-face clinical communications; caregiver access to consumer health information technology, e.g., patient portals to enhance communication with providers; and systematic identification of caregivers participating in care delivery, including their capacity, needs, and strengths.

Dr. Wolfe cited a recent study that showed a reduction in caregivers' emotional, physical, and financial difficulties from 1999 to 2015 and greater use of respite care, with the greatest impact on older caregivers. She also identified promising areas for improvement, for example, data Infrastructure for monitoring and surveillance in care delivery settings and family experiences of care; interprofessional, team-based, family-centered care; and more comprehensive support of caregivers.

In his presentation, Dr. Philip Sloane of the University of North Carolina noted that caregivers of patients with AD and other forms of dementia often manage multiple comorbidities because they tend to be older. This places caregivers at risk for injury and higher illness burden, and saddles them with decision-making responsibilities, yet they get little support. Dr. Sloane's research has revealed how often dementia caregivers have dealt with worsening organ-specific symptoms, in addition to behavioral and non-specific symptoms, which require decision-making. These findings have contributed to guidance in caregiver skills training, for example, acting fast, assessing vital signs and dehydration, and identifying pain.

Dr. Sloane has developed a training website to inform caregivers on what to do when evaluating symptoms, as well as how to interact with the health care system. This access to resources improved caregivers' confidence. Because approximately one-third of dementia caregivers don't use the internet, he reproduced the material in a book, with an emphasis on brevity and visual appeal. Dr. Sloane noted the need for more guidance on common, challenging symptoms, especially those most associated with hospitalization and emergency department visits: organ-specific (e.g., urinary tract

infections), non-specific symptoms (decreased activity, not eating), and changes in mental status.

Resources for the management of caregivers' own chronic conditions were addressed in the Plenary 5 discussion. Elderly caregivers are generally part of a health care system already, but health care providers can help these caregivers to ask for help from their networks. Additional resources can be developed to help health care providers make referrals to resources. Small support services, such as respite care, can be very helpful to caregivers. However, some families don't qualify for volunteer services, which are otherwise quite expensive and many families are reluctant to spend money on self-care.

It was noted that a dearth of evidence-based policies to address home care costs and insurance reimbursement demands more health economists in research, yet cost-effectiveness is not always the best route to quality. There is also an ongoing challenge to disseminate and implement evidence-based interventions into the thousands of homes that need them. The importance of implementation science was emphasized, as well as the involvement of community-based services. The need for implementation of interventions, in turn, informs research and development of interventions. As with caregiver research of other serious illnesses, the focus of dementia caregiver research is on spouses. However, adult children or neighbors are frequently caregivers of these older adults. To address this concern, research can be conducted on specific populations of caregivers or interventions can be studied in a range of settings to measure their impact.

Closing Keynote: Bringing Voices Together

Dr. Gitlin concluded the symposium by articulating the changes in the science of caregiving over time, with new constructs, methodologies, theory development, and myth-busting. Demographic changes mean more men and teenagers are involved in

caregiving. Across all conditions, caregiving tasks change and accumulate over time. As well, caregivers' needs change over the life course and depending on the care recipients' condition and disease stage. The governmental policies and services to support them through these transitions are not apparent.

Dr. Gitlin noted the requirement for new measures of the complexity of caregiving. Although interventions have improved, early models still have not made it into health systems. She emphasized the importance of utilizing implementation science early in the development of interventions to achieve the goal of widespread use.

A simple solution to many issues would be helping families at intersections with the health care system and identifying universalities and caregiving tasks. Conflict management (in the health care system and within the family), communication, problem-solving, specialized knowledge and skills, self-care advocacy, and care of other family members are common topics across caregiver populations.

Closing Remarks:

Dr. Marguerite Littleton Kearney, Director of NINR's Division of Extramural Science Programs, noted that caregiving touches everyone. She acknowledged the summit's accomplishment in highlighting the issues and pressures of caregiving and their impact on caregiver health. Dr. Kearney extended thanks to the attendees and their thoughtful questions, and the presenters for their insights, as well as the summit's partners and co-sponsors. She added that the information gained during the summit will guide further research and evidence-based strategies that will hopefully improve caregivers' and care recipients' quality of life.