# Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop

## Committee

## Grace B. Campbell

**Co-Chair**

Grace Campbell, Ph.D., M.S.W., RN, CNL, CRRN, FARN is an Assistant Professor at the Duquesne University School of Nursing. She also holds adjunct appointments at the University of Pittsburgh School of Medicine, Department of Obstetrics, Gynecology, and Reproductive Science and the University of Pittsburgh Hillman Cancer Center Biobehavioral Oncology Group. She is a founding faculty member of the UPMC Magee Gynecologic Oncology Family Caregiver Advocacy, Research, and Education (CARE) Center. Her research focuses on characterizing and intervening on cancer- and treatment-related functional limitations. She is currently Co-Lead for “SmartRehab: mHealth A Systemwide Scale-Up Project” at the University of Pittsburgh’s National Center on Family Support, funded by the National Institute for Disability, Independent Living, and Rehabilitation Research.

Dr. Campbell is a Certified Rehabilitation Registered Nurse and a Fellow of the Association of Rehabilitation Nurses. (ARN) She is a member of the Board of Directors of ARN and represents that organization on the NASEM Roundtable on Quality of Care for People with Serious Illness. She was a member of the 2021 NASEM Consensus Study Report, “Diagnosing and Treating Adult Cancers and Associated Impairments.” She is a member of the American Society for Clinical Oncology, serving as a Quality Training Program Coach. She is also a member of the Oncology Nursing Society, American Congress of Rehabilitation Medicine’s Cancer Networking Group, and the Multinational Association of Supportive Care in Cancer.

## Randall A. Oyer

**Co-Chair**

Randall A. Oyer, M.D. is a practicing medical oncologist at the Ann B. Barshinger Cancer Institute at Penn Medicine Lancaster General in Lancaster, Pennsylvania. Dr. Oyer serves as the Medical Director of the Cancer Institute, Medical Director of Oncology, Chairman of Cancer Committee, Chair of the Oncology Physicians Advisory Council, and Medical Director of the Cancer Risk Evaluation Program at Penn Medicine Lancaster General. Dr. Oyer is a member of the Cancer Service Line Executive Committee and the Cancer Service Line Quality Committee at the Abramson Cancer Center- University of Pennsylvania, Philadelphia.

Dr. Oyer is also a member of the Board of Directors, and Immediate Past President of the Association of Community Cancer Centers, Rockville, Maryland. Dr. Oyer is an ex-officio Commissioner of the American College of Surgeons Commission on Cancer, representing the Association of Community Cancer Centers. He also is a member of the National Cancer Policy Forum at the National Academies of Science, Engineering, and Medicine.

## Allison Applebaum

**Member**

Allison Applebaum, Ph.D., is an Associate Attending Psychologist in the Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center (MSK), and an Associate Professor of Psychology in Psychiatry at Weill Cornell Medical College. She is the Founding Director of the Caregivers Clinic at MSK, housed in the Counseling Center. The Caregivers Clinic is the first of its kind and provides comprehensive psychosocial care to family members and friends of patients who experience significant distress and burden as a result of their caregiving role. Dr. Applebaum's program of research focuses on the development and dissemination of psychosocial interventions for cancer caregivers, as well as understanding the impact of caregiver psychosocial wellbeing, prognostic awareness and communication skills on advanced care planning. She has published over 100 articles, reviews, and book chapters on these topics, and is the editor of the textbook Cancer Caregivers (Oxford University Press, 2019). Dr. Applebaum has received competitive funding for her research, including awards from the National Cancer Institute, the National Institute of Nursing Research, the American Cancer Society, the T.J. Martell Foundation, and the van Ameringen Foundation.

## Jennifer M. Ballentine

**Member**

Jennifer Moore Ballentine, M.A., has more than 20 years' experience in hospice and palliative care, healthcare ethics and public policy, adult education, change design, and nonprofit leadership. As Executive Director of the California State University Shiley Haynes Institute for Palliative Care, she oversees this unique enterprise developing innovative online and in-person curriculum for palliative care clinicians and other healthcare professionals caring for people with serious illness worldwide, as well as students in the healthcare professions throughout the CSU system. Her past leadership positions include President of The Iris Project; Vice President for Hospice Analytics; Executive Director of Life Quality Institute; and Director of Professional Programs for the Colorado Center for Hospice and Palliative Care. She also serves with several national projects committed to improving quality in palliative care: the NHPCO Palliative Care Advisory Council, the Patient Quality of Life Coalition Steering Committee, and the National Academy of Medicine Roundtable on Quality Care of People with Serious Illness. Jennifer has presented hundreds of educational workshops and keynotes at state and national conferences and is published widely in clinical literature, textbooks, and trade press. Jennifer holds a Master's degree with graduate honors in End-of-Life Studies from Regis University, a professional advancement certificate in gerontology from University of Colorado–Colorado Springs, and a Bachelor's degree, Phi Beta Kappa, from Oberlin College.

## Cathy Bradley

**Member**

Cathy J. Bradley, Ph.D., is the Associate Dean for Research in the Colorado School of Public Health and the Deputy Director of the University of Colorado Cancer Center. She holds the Bunn Chair in Cancer Research. Prior to joining the University of Colorado, she was the founding Chair of the Department of Healthcare Policy and Research, and Associate Director of Cancer Prevention and Control at Virginia Commonwealth University School of Medicine. Dr. Bradley is an internationally recognized expert in health services research and health economics. Her expertise is in labor market outcomes of cancer survivors, health policy, and health disparities. Dr. Bradley is on the editorial board of the Journal of Cancer Survivorship, and is a member of the National Academies of Sciences, Engineering, and Medicine National Cancer Policy Forum.

## Julie Bynum

**Member**

Julie Bynum, M.D., M.P.H. is the Margaret Terpenning Professor of Internal Medicine in the Division of Geriatric and Palliative Medicine, Vice Chair for Faculty Affairs for the Department of Internal Medicine, Research Professor in the Institute of Gerontology, Geriatric Center Associate Director for Health Policy and Research, and a member of the Institute for Healthcare Policy and Innovation. Dr. Bynum received her medical and public health degrees from Johns Hopkins, did her residency and chief residency at Dartmouth, and completed specialty training in Geriatric Medicine back at Johns Hopkins. She then joined the faculty at Dartmouth Medical School where she received prestigious career development awards from the Robert Wood Johnson Physician Faculty Scholar Program and the National Institute of Aging Beeson Scholar Program before joining the faculty at University of Michigan. She is known for leading interdisciplinary research teams to study questions about the complex drivers of quality and costs for older adults and how to improve health care policy and performance using national administrative data, particularly for people living with dementia or nearing the end of life. In addition, she has been an Atlantic Philanthropies Health & Aging Policy Fellow, was a member of the National Academy of Medicine Committees that published “Vital Signs: Core Metrics for Health and Health Care Progress” and was recently a Deputy Editor of the Journal of the American Geriatrics Society. She is currently a member of the National Academy of Medicine Forum on Aging, Disability and Independence and on a NAM Consensus Committee on “Building Data Infrastructure for Patient Centered Research.” Dr. Bynum leads a robust portfolio of research largely focusing on health and health care for people living with dementia including a National Institute of Aging P30 Center to Accelerate Population Research in Alzheimer’s and studies that examine the quality of care, diagnosis, and treatment of people with living with dementia in the community, longterm care, and assisted living.

## Jane Carmody

**Member**

Jane Carmody, DNP, M.B.A., RN, FAAN is a Senior Program Officer at The John A. Hartford Foundation, a national private foundation dedicated to improving the care of older adults. Her portfolio of grants includes programs to create age-friendly public health systems, strengthen community-based services for older adults, disseminate dementia care programs and resources, and improve emergency department care and surgical care for older adults.

## Sara Damiano

**Member**

Sara Damiano, LMCW, MSG, CCM, ACHP-SW is the Ascension national director of palliative care overseeing the strategy and services of 200 specialty level staff, spanning across 12 markets, in 55 inpatient locations, 19 outpatient clinics, and 2 community based locations. In this role, she is responsible for the overall palliative care strategy with a focus on increasing access and referrals to specialty level palliative care services, enhancing primary palliative care, and integration with population health and value based care initiatives. Previously, she served as the palliative care system director at Michigan’s largest healthcare system-Beaumont Health, where she was responsible for leading the corporate strategy and operations for the clinical service line across 8 hospitals and outpatient services. Earlier in her career, she served as a manager of care management with Alliance Health, as a research recruiter with the San Francisco Public Health Department, and as a disability examiner with Social Security Disability. She has more than 10 years of health care experience with leadership roles in palliative care, advance care planning, and care management. She is a licensed clinical social worker, certi?ed case manager, and holds advanced certi?cation in hospice and palliative care as a social worker. She earned a dual master's degree from the University of Southern California, Los Angeles in social work and gerontology as well as a bachelor’s degree in sociology with a minor in gender and health from the University of Michigan, Ann Arbor. She is a member of the National Association of Social Workers, American College of Healthcare Executives, and American Academy of Hospice and Palliative Medicine.

# Pamela S. Hinds

**Member**

Pamela S. Hinds, Ph.D., RN, FAAN is the Executive Director of the Department of Nursing Science, Professional Practice, and Quality, the William and Joanne Conway Endowed Chair in Nursing Research, and the Research Integrity Officer at Children's National Health System in Washington, D.C., and a Professor of Pediatrics at the George Washington University, School of Medicine and Health Sciences in Washington, D. C. She is adjunct professor for the University of Pennsylvania, School of Nursing, Johns Hopkins University, School of Nursing, the University of Maryland, College of Nursing, and the Fudan University of Shanghai, China. Dr. Hinds received her undergraduate degree magna cum laude from the University of Vermont, Burlington, VT and her M.S.N. and Ph.D. degrees from the University of Arizona, Tucson in Psychiatric Nursing (summa cum laude) and Clinical Nursing Research, respectively. For more than three decades, Dr. Hinds has created and led research related to the pediatric cancer experience, quality of life, fatigue and altered sleep during the treatment of pediatric cancers, and end-of-life communication and decision making. She served on the Institute of Medicine (IOM) committee on end-of-life and palliative care for children in America (2003) and the National Quality Forum panel on palliative and end-of-life care in America, the Institute of Medicine (IOM) committee on Dying in America (2014) and is currently serving on the National Academies of Sciences, Engineering and Medicine Roundtable on Quality Care for People with Serious Illness (2016-2022), the NCI Moonshot Tolerability Steering Committee (2019-2021), and the Committee on Childhood Cancers and Disability (2020-2021). Dr. Hinds is an Oncology Nursing Society Distinguished Nurse Researcher and the Association of Pediatric Oncology and Hematology Distinguished Nurse Researcher. She was the inaugural chair of the Nurse Scholars for the Children’s Oncology Group and the inaugural Co-Director for the Patient-Reported Outcomes (PRO) Resource Center for the Children’s Oncology Group. She served on the National Cancer Institute Symptom and Quality of Life Scientific Committee, and the National Institute of Nursing Research Ad Hoc Evaluation Advisory Committee, End-of-life and Palliative Care Science, and is the Editor-in-Chief for the journal, CANCER NURSING: An International Cancer Journal. Dr. Hinds was named the Alumna of the Year in 2012 for the College of Nursing at the University of Arizona, received the 2015 Mentoring Award for Excellence in Clinical Research at Children’s National Health System, and received the inaugural Nancy Klein Mentoring Award from the Association of Hematology/Oncology Nurses in 2016. She is the 2020 recipient of the HPNA Distinguished Nurse Researcher Award in Palliative Care and the 2020 Nightingale Award from the American Nurses Association and the Washington Post.

# Randall A. Jones

**Member**

Randy A. Jones, Ph.D., RN, FAAN is a tenured Full Professor and the Associate Dean for Partner Development and Engagement at the University of Virginia School of Nursing and the Assistant Director of Outreach Recruitment and Engagement at the University of Virginia Comprehensive Cancer Center.

Throughout his career of continuous research funding, Jones has been committed to advancing health equity, diversity, community engagement, and interprofessional collaborations as it relates to research, teaching, service. His research and publications focus on health disparities, prostate cancer, chronic illness, and decision-making. He has conducted multiple studies on screening and treatment decision making as it relates to cancer, with an emphasis among African Americans. His program of research has expanded to include palliative care and caregivers' interactions with patients. He has received funded research grants (over $11.5 million) from organizations such as the National Institutes of Health (NIH), Robert Wood Johnson Foundation, American Cancer Society, and the American Nurses Foundation. He is currently Principal Investigator on a NIH R01 funded study testing an interactive decision aid for patients with advanced prostate cancer. Jones' program of research in developing and testing an interactive decision aid for those men who were diagnosed with advance prostate cancer may help patients with prostate cancer make informed, shared decisions about treatment. His program of research has implications for other chronic illnesses as well. Jones research aims to help decrease decisional regret and enhance quality of life among patients with chronic diseases and aid in better patient-centered care and precision medicine.

Jones' national reputation in health disparities and cancer research, has resulted in a number of recognitions, awards and honors. In addition, he has been invited to serve on several national and international impactful organization boards, such as the National Black Nurses Association, the National Institutes of Health, American Academy of Nursing, the Oncology Nursing Society, the Robert Wood Johnson Foundation, and The National Academies of Medicine's National Cancer Policy Forum, to name a few. He has published extensively in peer-reviewed journals.

## Rebecca A. Kirch

**Member**

Rebecca A. Kirch, J.D. is EVP of Policy and Programs for the National Patient Advocate Foundation (NPAF) based in Washington, DC. In this role, she provides strategic focus and leadership in bringing patient and caregiver voices and values to the forefront of health reform efforts through influential advocacy and grassroots mobilization. As a leading health policy expert and advocate in her field, Rebecca is dedicated to advancing person-centered policies and practices that put people at the heart of healthcare.

Prior to joining NPAF in 2016, she served for 15 years with the American Cancer Society and its advocacy affiliate, the American Cancer Society Cancer Action Network, directing development and execution of coordinated quality of life and survivorship research, policy and advocacy activities. A frequently invited speaker on patient and family engagement about person-centered care priorities and practices, Rebecca has authored numerous articles and book chapters, including publications in the New England Journal of Medicine, Archives of Internal Medicine, Health Equity, JAMA Oncology, Health Affairs, Circulation and other professional journals. She is the recipient of numerous national awards, has been featured in multiple media outlets and also serves on National Quality Forum's MAP Coordinating Committee and Consensus Standards Approval Committee and ICER's New England Comparative Effectiveness Public Advisory Council. Among other advisory committees and advocacy coalitions, Rebecca is currently an active participant of the National Academy of Science, Engineering and Medicine's Quality Care for People with Serious Illness Roundtable, co-chair of the Quality of Life and Person-Centered Care task force for the American Congress of Rehabilitation Medicine and a board member for children's oncology Care Camps.

## Amy Melnick

**Member**

Amy Melnick, M.P.A. is the Executive Director of the National Coalition for Hospice and Palliative Care (NCHPC). Amy's career has focused on health care policy, legislative and regulatory advocacy, and Coalition building with diverse stakeholders. Amy guides the Coalition efforts towards improved communication, coordination and collaboration within the 13 national organizations representing the interdisciplinary hospice and palliative care field. Prior to joining the Coalition, Amy led public policy and advocacy efforts for the Arthritis Foundation and Heart Rhythm Society after serving on Capitol Hill for several years. Amy attended the London School of Economics and Political Science and received her undergraduate degree from Wellesley College and her Master of Public Administration from George Mason University.

# Clyde W. Oden, Jr.

**Member**

The Reverend Doctor Clyde W. Oden, Jr., has served low-income communities of color, focusing on health care services and religious ministries. He is an optometrist and a retired health executive after serving for three decades as chief executive officer of one of the nation's largest Federal Qualified Health Centers (FQHCs) and retired as a pastor in the African Methodist Episcopal Church (AMEC), leading three Southern California congregations over nearly a quarter of a century.

He is currently the Assistant Director of the Alameda County Health Care Alliance. The ACCA specializes in faith-based lay care navigation and intervention programs that serve individuals with advanced illness and their caregivers. This nonprofit community organization serves persons in Alameda, Contra Costa, and San Francisco counties.