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# Editorial Board

**Lynda Anderson, PhD**

Centers for Disease Control and Prevention  
National Center for Chronic Disease Prevention and Health Promotion  
Division of Adult and Community Health  
Healthy Aging Program  
1600 Clifton Road  
Atlanta, GA 30333

**Amanda Smith Barusch, PhD**

University of Otago  
Department of Social Work and Community Development  
Dunedin, New Zealand

**James R. Bitter, PhD**

East Tennessee State University  
School of Graduate Studies  
309-B Burgin Dossett Hall  
PO Box 70720  
Johnson City, TN 37614-0720

**Michael B. Blank, PhD**

University of Pennsylvania  
Center for Mental Health Policy and Services Research  
Department of Psychiatry  
3535 Market St., Suite 3020  
Philadelphia, PA 19104-3309

**Ralph B. Brown, PhD**

Brigham Young University  
Department of Sociology  
2230 Canyon Rd., 2034 JFSB  
Springville, UT 84663

**Mayling Chu, PhD**

California State University, Stanislaus  
Department of Social Work  
One University Circle  
Turlock, CA 95382

**Judith A. Crews, PhD**

Idaho State University  
Department of Counseling  
ISU-Meridian Health Science Center  
1311 E Central Drive  
Meridian, ID 83642

**Jeanette R. Davidson, PhD, ACSW**

University of Oklahoma  
African and African-American Studies  
Physical Science Building, Room 517  
601 Elm Avenue  
Norman, OK 73019–3120

**Cheryl E. Easley, PhD, RN**

University of Alaska Anchorage  
College of Health and Social Welfare  
3211 Providence Drive  
Anchorage, Alaska 99508

**Gary P. Green, PhD**

University of Wisconsin-Madison  
Department of Community & Environmental Sociology  
346D Agricultural Hall  
1450 Linden Drive  
Madison, WI 53706

**Rick Greene, MSW**

U.S. Department of Veterans Affairs  
Office of Geriatrics & Extended Care  
810 Vermont Avenue, NW  
Washington, DC 20420

**James A. Kulik, PhD**

University of California, San Diego  
Department of Psychology  
9500 Gilman Drive #0109  
La Jolla, CA 92093–0109

**John Paul Marosy**

Bringing Elder Care Home LLC  
52 Holden Street  
Worcester, MA 01605

**Pamela L. Mulder, PhD**

Marshall University  
Department of Psychology  
400 Hal Greer Blvd, Harris Hall 323  
Huntington, WV 25755

**Katherine C. Nordal, PhD**

The Nordal Clinic  
1121 Grove Street  
Vicksburg, MS 39183

**Dena C. Puskin, ScD**

U.S. Department of Health and Human Services  
Office for the Advancement of Telehealth  
5600 Fishers Lane, Rm. 7C-22  
Rockville, MD 20857

**Thomas Riley, PhD**

North Dakota State University  
College of Arts, Humanities and Social Sciences  
Putnam 105, Department #2300  
P.O. Box 6050  
Fargo, ND 58108-6050

**Teresa R. Sobieszczyk, PhD**

University of Montana  
Department of Sociology  
Social Sciences 303  
Missoula, MT 59812



Ronda C. Talley • Kathleen Chwalisz  
Kathleen C. Buckwalter  
Editors

# Rural Caregiving in the United States

Research, Practice, Policy

 Springer

*Editors*

Ronda C. Talley, Ph.D., MPH  
Suzanne Vitale Clinical  
Education Complex  
School of Education  
Western Kentucky University  
104 14th Avenue  
Bowling Green, KY 42101, USA  
ronda.talley@wku.edu

Kathleen Chwalisz, Ph.D  
Department of Psychology  
Southern Illinois University Carbondale  
Carbondale, IL 62901, USA  
chwalisz@siu.edu

Kathleen C. Buckwalter, Ph.D  
John A. Hartford Center  
of Geriatric Nursing Excellence  
College of Nursing  
University of Iowa  
494 NB, 50 Newton Road,  
Iowa City, IA 52242, USA

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*This book is dedicated to the memory  
of Mary Starke Harper, one of the nation's  
leading advocates for improving health care  
for rural caregivers, minorities, the elderly,  
and the mentally ill.*



# Foreword

From its inception in 1987, the Rosalynn Carter Institute for Caregiving (RCI) has sought to bring attention to the extraordinary contributions made by caregivers to their loved ones. I grew up in a home that was regularly transformed into a caregiving household when members of my family became seriously ill, disabled or frail with age, so my interest in the issue is personal. In my hometown of Plains, Georgia, as in most rural communities across our country, it was expected that family members and neighbors would take on the responsibility of providing care whenever illness struck close to home. Delivering such care with the love, respect and attention it deserves is both labor-intensive and personally demanding. Those who do so represent one of this nation's most significant yet underappreciated assets in our health delivery system.

When the RCI began, "caregiving" was found nowhere in the nation's health lexicon. Its existence was not a secret but rather simply accepted as a fact of life. In deciding on the direction and priorities of the new institute, we convened groups of family and professional caregivers from around the region to tell their personal stories. As I listened to neighbors describe caring for aged and/or chronically ill or disabled family members, I recognized that their experiences reflected mine. They testified that while caregiving for them was full of personal meaning and significance and could be extremely rewarding, it could also be fraught with anxiety, stress, and feelings of isolation. Many felt unprepared and most were overwhelmed at times. A critical issue in the "field" of caregiving, I realized, was the need to better understand the kinds of policies and programs necessary to support those who quietly and consistently care for loved ones.

With the aging of America's Baby Boomers expecting to double the elderly population in the next 20 years, deinstitutionalization of individuals with chronic mental illnesses and developmental disabilities, a rising percentage of women in the workforce, smaller and more dispersed families, changes in the role of hospitals, and a range of other factors, caregiving has become one of the most significant issues of our time. Caregiving as an area of research, as a focus and concern of policy making, and as an area of professional training and practice has reached a new and unparalleled level of importance in our society and indeed globally.

As we survey the field of caregiving today, we recognize that it is an essential component of long-term care in the community, yet also a potential health risk for those who provide care. The basic features of a public health approach have emerged: a focus on populations of caregivers and recipients, tracking and surveillance of health risks, understanding the factors associated with risk status, and the development and testing of the effectiveness of various interventions to maximize benefits for both the recipients of care and their providers.

The accumulated wisdom from this work is represented in the volumes that make up the Springer Caregiving Series. This series presents a broad portrait of the nature of caregiving in the United States in the twenty-first century. Most Americans have been, are now, or will be caregivers. With our society's increasing demands for care, we cannot expect a high quality of life for our seniors and others living with limitations due to illness or disability unless we understand and support the work of caregivers. Without thoughtful planning, intelligent policies, and sensitive interventions there is the risk that the work of family, paraprofessional, and professional caregivers will become intolerably difficult and burdensome. We cannot let this happen.

Readers of this series will find hope and evidence that improved support for family and professional caregivers lies within our reach. The field of caregiving has matured and, as evidenced in these volumes, has generated rigorous and practical research findings to guide effective and enlightened policy and program options. My hope is that these volumes will play an important role in documenting the research base, guiding practice, and moving our nation toward effective policies to support all of America's caregivers.

Rosalynn Carter

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## About the Editors

**Ronda C. Talley, Ph.D., MPH,** is Executive Director of the Suzanne Vitale Clinical Education Complex at Western Kentucky University and Professor of Psychology. Her prior work experience includes serving as Executive Director of the Rosalynn Carter Institute for Caregiving; Associate Director of Legislation, Policy, and Planning/Health Scientist at the Centers for Disease Control and Prevention; and Associate Executive Director at the American Psychological Association. Dr. Talley received the Outstanding Alumni Award from Indiana University and the Jack Bardon Distinguished Service Award from the Division of School Psychology of the American Psychological Association. Dr. Talley may be reached at 104 14th Avenue, Bowling Green, KY 42101; by telephone at (270) 745-2780; or via e-mail at [ronda.talley@wku.edu](mailto:ronda.talley@wku.edu).

**Kathleen Chwalisz, Ph.D.,** is professor of psychology and family and community medicine at Southern Illinois University, Carbondale. She is codirector of the Southern Illinois Rural Caregiver Telehealth Project and training director of the SIUC Counseling Psychology Doctoral Program. She may be reached at the Department of Psychology, SIUC, Carbondale, IL 62901; by telephone at (618) 453-3541; or via e-mail at [chwalisz@siu.edu](mailto:chwalisz@siu.edu).

**Kathleen C. Buckwalter, Ph.D., RN, FAAN,** is Sally Mathis Hartwig professor of Gerontological Nursing Research and Director of the John A. Hartford Center of Geriatric Nursing Excellence, College of Nursing, University of Iowa. She may be reached at 494 NB, 50 Newton Road, Iowa City, IA 52242; by telephone at (319) 335-7083; or via e-mail at [kathleen-buckwalter@uiowa.edu](mailto:kathleen-buckwalter@uiowa.edu).





## Contributors

**Cliff Burt, MPA** is Aging Services Coordinator in the Division of Aging Services of the Georgia Department of Human Resources. He may be reached at 2 Peachtree Street, NW, Suite 9-470, Atlanta, GA 30303; by telephone at (404) 657-5336; or via e-mail at [gcburt@dhr.state.ga.us](mailto:gcburt@dhr.state.ga.us).

**Joshua C. Byrd** a senior program coordinator in the Center on Aging West Virginia University. He may be reached at P.O. Box 9127, Morgantown, West Virginia 26506; by telephone at 304-293-1796; or via e-mail at [jbyrd@hsc.wvu.edu](mailto:jbyrd@hsc.wvu.edu).

**Patricia A. Calico, DNS, RN** is a consultant based in Stanford, KY. She may be reached at 85 Henry Clay Rd, Stanford, KY 40484, by telephone at 606-355-7891, or via e-mail at [calico1@netscope.net](mailto:calico1@netscope.net). Dr. Calico is former branch chief, Advanced Education Nursing, Division of Nursing, Bureau of Health Professions, Health Resources and Services Administration, US Department of Health and Human Services.

**Stephanie M. Clancy Dollinger, Ph.D.** is Co-Director of the Southern Illinois Caregiver Telehealth Project (<http://www.tlc.siu.edu/>) funded by the National Institute of Aging and National Institute of Nursing Research. Dr. Dollinger teaches undergraduate classes in Adolescence and Adulthood and Aging, and teaches graduate seminars in Life Span Developmental Theory and Cognitive Aging. She also serves as director of the Undergraduate Psychology Honors Program. She can be reached at [smcd@siu.edu](mailto:smcd@siu.edu).

**Stacey Cole, BS** is at the University of California, Davis.

**Linda Lindsey Davis, Ph.D., RN, FAAN** is the Ann Henshaw Gardiner professor at the Duke University School of Nursing, and is a Senior Fellow in the Center for the Study of Aging and Human Development, Duke University Medical Center. She may be reached at the Duke University Medical Center, 307 Trent Drive, Duke University, Durham, NC 27710; by phone at 919-684-0343; or via e-mail at [davis317@mc.duke.edu](mailto:davis317@mc.duke.edu).

**Catherine Lynch Gilliss, DNSc, RN, FAAN** is Dean of the Duke University School of Nursing, and Vice Chancellor for Nursing Affairs, Duke University Health

Sciences. She may be reached at Duke University Medical Center, 307 Trent Drive, Durham, NC 27710; via phone at 919-684-3786 x225; or by e-mail at catherine.gilliss@duke.edu.

**R. Turner Goins, Ph.D.** is an associate professor in the Department of Community Medicine and Center on Aging, West Virginia University. She may be reached at P.O. Box 9127, Morgantown, West Virginia 26506; by telephone at 304-293-3129; or via e-mail at rgoins@hsc.wvu.edu. Reprint requests should be addressed to Dr. Goins.

**Maria Greene, MS** is Director of the Division of Aging Services in the Georgia Department of Human Resources. She may be reached at 2 Peachtree St. NW, 9th Floor, Atlanta, Georgia 30303; by telephone at (404) 657-5252; or via e-mail at magreene@dhr.state.ga.us.

**Tawanda M. Greer, Ph.D.** is Assistant Professor in the Department of Psychology and Women's Studies, Barnwell College, University of South Carolina. She may be reached at 525a Barnwell College, Columbia, SC 29208; by telephone at (803) 777-6413; or via e-mail at tmgreer@sc.edu.

**Mary Starke Harper, Ph.D., RN, FAAN** deceased in 2006 at age 86. Dr. Harper began her 65-year medical career as a nurse in Alabama, to whom this book is dedicated, caring for an aging George Washington Carver. She became one of the nation's leading advocates for improving health care for minorities, the elderly, and the mentally ill. Dr. Harper spent many years as a nurse in veteran's hospitals, then became a policymaker with the National Institutes of Health and an adviser to four presidents. She also helped begin an NIH program that has trained thousands of minority scientists and health-care workers. Dr. Harper was the last surviving participant in the notorious Tuskegee syphilis project, a U.S. Public Health Service study in which black men in Macon County, AL, were deliberately left untreated to determine the long-term effects of the often fatal venereal disease. Years later, after a conscience-stricken Dr. Harper understood her unwitting role in the project, she vowed to change the way the government conducted studies on people. She William Jefferson served on White House advisory panels for every president from Jimmy Carter to Clinton. She was on the board of directors of the National Mental Health Association and consulted with NIH, Johnson & Johnson, and the Rosalynn Carter Institute for Caregiving.

**Brianne McCarthy Stanback, MFYCS** is at the University of South Florida. She may be reached at bmccart2@mail.usf.edu.

**Martin Morthland, M.Phil.** is PEARL project coordinator in the Department of Psychology at the University of Alabama. He may be reached at Box 870348, 367C Gordon Palmer Hall, Tuscaloosa, AL 35487; by telephone at (205) 348-0274; or via e-mail at pearl@bama.ua.edu.

**Thomas Nesbitt, M.D., MPH** is executive associate dean for Administration and Clinical Outreach and Professor in the Department of Family and Community Medicine. Dr. Nesbitt specializes in rural health and the use of advanced telecommunications technologies to improve access to medical education and care. He may be reached at 4610 X Street, Sacramento, CA 95817; or by telephone at (916) 734-3578.

**Molly M. Perkins, Ph.D.** is a research associate at the Rollins School of Public Health at Emory University. She may be reached at the Department of Behavioral Sciences and Health Education at 1518 Clifton Road, NE, Room 534; by telephone at 404-727-2861; or via e-mail at [mmperki@emory.edu](mailto:mmperki@emory.edu).

**Kathy L. Reschke, Ph.D.** is Early Development & Learning Consultant with ChildWise Resources. She may be reached at 41 Central Avenue, Westerville OH 43081; by telephone at (614) 899-7292; or via e-mail at [kreschke@childwiseresources.com](mailto:kreschke@childwiseresources.com).

**Forrest Scogin, Ph.D.** is professor in the Department of Psychology at the University of Alabama. He may be reached at 367C Gordon Palmer Hall, Tuscaloosa, AL 35487; by telephone at (205) 348-1924; or via e-mail at [fscogin@as.ua.edu](mailto:fscogin@as.ua.edu).

**Kathy Scott, Ph.D., RNC** is President of Programs Assisting Community Elderly, Inc. Dr. Scott may be reached at 11205 Alpharetta Hwy, Suite B1-A, Roswell, GA 30076; by telephone at (770) 754-3146; or via e-mail at [cbscott@mindspring.com](mailto:cbscott@mindspring.com).

**S. Melinda Spencer, Ph.D.** is an assistant professor in the Department of Health Promotion, Education, and Behavior at the University of South Carolina. She may be reached at 800 Sumter Street, Room 216, Columbia, South Carolina 29208; by telephone at (803) 777-7096; or via e-mail at [spencer.mindi@gmail.com](mailto:spencer.mindi@gmail.com).

**Vivian L. Tamkin** received her Ph.D. from Southern Illinois University Carbondale.

**Susan K. Walker, Ph.D.** is associate professor in the Department of Curriculum and Instruction at the University of Minnesota. She may be reached at 235 Peik Hall, 159 Pillsbury Drive SE, Minneapolis, MN 55455-0208; by telephone at (612) 624-1273; or via e-mail at [skwalker@umn.edu](mailto:skwalker@umn.edu).

**Carolyn S. Wilken, Ph.D.** is associate professor and Extension Gerontologist in Family, Youth and Community Sciences at the University of Florida. She may be reached at P.O. Box 110310, 3031 McCarty Hall D, Gainesville, FL 32611-0310; by telephone at 352-392-2201x303; or via e-mail at [cswilken@ifas.ufl.edu](mailto:cswilken@ifas.ufl.edu).

**Peter Yellowlees, MBBS, MD** is professor of psychiatry and director of Academic Information Systems at University of California at Davis. Dr. Yellowlees is a psychiatrist who has worked in public and private sectors, in academia, and in rural settings. He has published three books and over 150 scientific articles and book chapters and has been regularly involved in media presentations. He has consulted to governments and private sector companies in several countries and has received about \$5million in research grants. His main interests are in improving access to health and education services using information technologies. Dr. Yellowlees may be reached at 2230 Stockton Blvd., CA 95817; by telephone at (916) 734-2972; or via e-mail at [peter.yellowlees@ucdmc.ucdavis.edu](mailto:peter.yellowlees@ucdmc.ucdavis.edu).

**Erin O'Neill Zerth** earned her Ph.D. in the Department of Psychology at Southern Illinois University Carbondale.

