The Rosalynn Carter Institute for Caregiving Book Series: Research, Policy and Practice
Background

- Initiated in 2001
- Unique business/academic partnership
- To address areas of need in caregiving
Panel Topics

- Caregiving across the Professions
- Caregiving across the Lifespan
- Caregiving and Mental Health
- Building Community Capacity for Caregiving
- Caregiving and Disabilities
- Caregiving and Alzheimer’s Disease
- Caregiving and Cancer
- Intergenerational Caregiving
- Education, Training and Support Programs for Caregivers
- Rural Caregiving
Panelist Responsibilities:

- Attend a panel meeting, give a presentation on their topic, contribute to panel discussions
- Write a book chapter on their topic
- Identify what’s known and what’s needed on their topic in the areas of education and training, practice, research, and policy and advocacy.
TODAY:

- Rural Caregiving in the United States
  Kathleen Buckwalter, PhD, RN, FAAN
- Education and Support Programs for Caregivers
  Ronald W. Toseland, PhD
- Multiple Dimensions of Caregiving and Disability
  Timothy R. Elliott, PhD, ABPP
- Cancer Caregiving in the United States
  Barry J. Jacobs, PsyD
- Caregiving Issues and Management Certificate
  Leisa Easom, PhD, RN
Intro: Caregiving in Rural America: A Matter of Culture.
Chwalisz, Buckwalter, & Talley
Part I: Caregiving Populations

• **Family Caregiving: Implications for Rural Practice, Policy, Education and Research**
  L. Davis, C. Gilliss, & M. S. Harper

• **Elder Caregiving in Rural Communities**
  K. Buckwalter & L. Davis

• **Care for Children and Youth in Rural Areas**
  S. Walker & K. Reschke
Part II: Practice & Research Issues

- **Addressing Disparities in Rural Health**
  T. Greer

- **Mental Health Concerns for Caregivers in Rural Communities**
  M. Morthland & F. Scogin

- **Research on Rural Caregiving**
  R.T. Goins, S.M. Spencer, & J. Byrd
Part III: Healthcare System Issues

- Workforce Issues in Rural Caregiving
  P. Calico

- Telemedicine: The Use of Information Technology to Support Rural Caregiving
  P. Yellowlees, T. Nesbitt, S. Cole
Part IV: Assistance Strategies

• **Education, Training and Support for Rural Caregivers**  
  K. Chwalisz, S. Clancy-Dollinger, E. O. Zerth, & V. Tamkin

• **Strategies to Support Rural Caregivers: Practice, Education & Training, Research, Policy & Advocacy**  
  C. Wilken & B. Stanback

• **State Responsibilities to Support Rural Caregiving: The Georgia Example**  
  M. Greene, M. Perkins, K. Scott, & C. Burt
Elder Caregiving in RURAL Communities

Kathleen C. Buckwalter
Linda L. Davis
Greying of RURAL America

• Minorities
• “Oldest Old”
• Low population density/large catchment areas
• Lack of access and reimbursement = barriers to community-based care
Service Acceptability

• Norms/values
• “Take care of their own”
• Families = direct/indirect care
• Challenges = out-migration
## Support for Informal Caregivers

<table>
<thead>
<tr>
<th>Reasons Caregivers Do Not Receive Assistance</th>
<th>Attitudinal Barriers</th>
<th>Structural Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not know they are eligible for caregiver assistance services</td>
<td>Stigma and guilt about seeking help and receiving services</td>
<td>Lack of coordination in the service delivery system</td>
</tr>
<tr>
<td>Are unaware that such programs exist in their community</td>
<td>Value of self-reliance</td>
<td>Service agencies that are overburdened, understaffed, or unavailable</td>
</tr>
<tr>
<td>Are too embarrassed to accept services they view as “welfare”</td>
<td>Belief that family members should be responsible for care</td>
<td>Distance and transportation</td>
</tr>
<tr>
<td>Are reluctant to seek services unless there is a “crisis”</td>
<td>Reluctance to seek services until a crisis occurs</td>
<td>Reimbursement policies for services are too restrictive</td>
</tr>
<tr>
<td>Find existing services too geographically distant to be helpful</td>
<td>Denial of symptoms</td>
<td>Lack of access to comprehensive diagnostic and assessment services</td>
</tr>
</tbody>
</table>

Ageism

Family physicians do not always make referrals for services
Strategies for Developing Successful Caregiver Assistance Programs in Rural Communities

• Offer programs suitable for both non-kin as well as kin caregivers
• Provide a variety of informational programs for caregivers on topics
• Offer preventive counseling as well as supportive mental health services for distressed and depressed caregivers
• Avoid labeling caregiver assistance programs with terms that may make them socially unacceptable or stigmatizing
Strategies, Con’t

• Provide transportation services for programs offerings, as well as home visitation services
• Offer caregiver “health promotion” programs in community centers during weekday, daytime hours so busy caregivers can combine self-care activities for themselves with a doctor’s appt. for the elder during a trip into town
• Provide telephone contact and referral service for “long-distance” caregivers for elders in the rural community
• Make local fund-raising activities a regular part of programs
• Staff programs with professional, paraprofessional and volunteer personnel who are knowledgeable about and sensitive to community culture and traditions as well as health care problems and service needs
RURAL Caregiver Program Planning Model

Relevance
Unity
Responsiveness
Access
Local Leadership
## RURAL Caregiver Program Planning Model

<table>
<thead>
<tr>
<th>Desired Program Characteristic</th>
<th>Program planners must ensure rural caregiver assistance programs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relevance</strong></td>
<td>Involve caregivers in identifying program service needs and program relevance</td>
</tr>
<tr>
<td><strong>Unity</strong></td>
<td>Integrate new program offerings with existing community services to insure the new program does not compete with or duplicate existing programs</td>
</tr>
<tr>
<td><strong>Responsiveness</strong></td>
<td>Are responsive to the ethnic and cultural identity and traditions of elders/caregivers/residents in the community</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td>Enhance program access for caregivers through timing, location, transportation and publicizing new services</td>
</tr>
<tr>
<td><strong>Local Leadership</strong></td>
<td>Include local leadership (nurses, social workers, physicians, ministers, church groups, civic leaders, other community service workers) in supporting and publicizing the program</td>
</tr>
</tbody>
</table>
Implications for Helping Elders and Their Caregivers in Rural Communities

- Implement needs assessment & data collections systems that accurately document the changing needs of rural elders & their informal caregivers
- Collaborate with local high schools & nearby community colleges to offer credit in visiting & working with frail elders & their caregivers
- Encourage health profession schools to include rural family caregiving courses in their curricula
- Project the need for rural health care service providers by discipline & offer more post-graduation incentives for providers who practice in rural communities.
Policy, Con’t

• Create articulated models of caregiver assistance programs between urban & rural health care centers
• Develop, implement & evaluate “promising Practice” models of caregiver assistance that are sensitive to the social, ethnic & geographic characteristics of rural communities
• Expand elder care insurance coverage to include informal caregiver education & skill training
• Provide state & federal funding for rural health centers through “dollar matching” grant mechanisms
Rural Caregiving: A Quilt of Many Different Colors
Talley, Chwalisz, & Buckwalter
Education and Support Programs for Caregivers: Research, Practice and Policy

Ronald W. Toseland, PhD
David H. Haigler, EdD
Deborah J. Monahan, PhD
Introduction

• Who are the caregivers – 21% of households

• Consequences of caregiving

• Demographic trends – living longer?

• Range of Education and Support programs
Hard-to-Reach Caregivers

• Benefits of education and support programs
• Identification, recruitment and engagement
• Common characteristics
• Group and Individually focused programs
• Barriers to Access
  - Predisposing
  - Enabling
  - Need
Utilization Patterns

• Emphasis on psycho-education and respite
• A lack of information
• Not for everyone
• How programs help
• Delaying institutionalization
  Can it be done?
  Is it a good thing?
• Cost effective?
Current Practices Across Health-Care Scenarios

- Clinic based programs
- Community Programs
- Home based programs
- Long distance programs
- Readiness programs
- Assessment as the key
- One size does not fit all!
Ethnic, Cultural and Gender Issues

• Ethnicity and culture in groups
• Gender in groups
• Adult Child, Spouse and Grandparents
• Empowerment groups
• African American culture
• Latino culture
• Lesbian, Gay, Bisexual and Transgender caregivers
Groups Leadership

- Peer-led
- Professional-led
- Training in leadership
- Manuals and workbooks
- Dementia and non-dementia
- Time to get more specific
- Hands on versus support
- Funding
Telehealth

• Review of Telehealth
• Telephone groups
• Video groups
• Internet groups chats, bulletin boards, video
• Band width and other access issues
• Rare diseases
• Need for research
Outcome Sustainability

- Proximal, Intermediate, and Distal
- Outcome limits, loss, lags
- Sustainability tests
  - Set reasonable goals
  - Match program content to participant needs
  - Match program length and intensity to goals
  - Anticipate and prepare for changes
  - Promote a comprehensive support strategy
  - Sustain the Program Itself
Evaluating Programs

- Aims
- Background and Theory
- Participant screening
- Design
- Program specification
- Measurement and measures
- Data analyses
- Human Subjects
Current and Future Directions
Recommendations

Professional Practice

– Close the gaps
– Broaden the focus and specialize
– Minority caregivers
– Use technology
– Broaden the definition of caregiver
– Pay attention to caregiving stages
Current and Future Directions Recommendations

Policy and Advocacy

– Uniform assessments with special modules
– Single point of entry
– Expand Family and Medical Leave Act
– Long term care insurance coverage
– Increase collaboration among consumers, policy makers, and practitioners
Multiple Dimensions of Caregiving and Disability

Timothy R. Elliott, Ph.D., ABPP
Texas A&M University
Defining Dimensions

Bulk of knowledge base concerns caregiving in age-related scenarios

Other scenarios
• Children with disabilities, SHCNs
• Acquired disabilities traumatic, chronic
• Aging parents of adults IDDs
• Grandparents as caregivers
• Children in caregiving roles
Consequences and Implications

Incomplete picture of family caregivers, *numbers lacking*

Lack of a coherent model of caregiving across scenarios

Separate silos of clinical service

Lack of comprehensive, informed policy
Similarities and Commonalities Across Scenarios

CGs are *de facto* extender of care

Policymakers view CG as a family obligation, *women will be there to supplement care as needed*

Costs to society are immense

Cuts to services for CGs presented as “cost-saving” measures *Medicaid, home-based services*
Rates of Disability are Increasing

Increasing number of people with chronic health conditions

Improved emergent care, longer life expectancy "epidemic of survival"

Some conditions require ongoing assistance that may necessitate a life-long commitment from a family member
Costs to Society Escalate with Returning Veterans in Elliott and Parker chapter

Signature wound: traumatic brain injury *polytrauma, PTSD*

TBI is a chronic disease process *cognitive deficits, neuroendocrine changes, pain, risk of mental health problems, CTE and dementia*

TBI and PTSD have increased risk of aggression, interpersonal abuse
Emerging Opportunities

Affordable Care Act (2010) resources, supports, facilitators

Increased attention from agencies, professional organizations

http://www.caregiver.va.gov/

http://www.dvbic.org/family-caregiver-curriculum

Who are the “people with disabilities”?

Traditionally defined by medical diagnostic conditions

Increase in the number of chronic health conditions and accompanying co-morbidities, secondary complications

Affects the “count” - one out of five, one out of four  
"Crews chapter"
ICF Model of Disability

from Crews chapter,
Holms & Raina chapter
<table>
<thead>
<tr>
<th>Body Functions &amp; Structures</th>
<th>Activities &amp; Participation</th>
<th>Environmental Factors</th>
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<tbody>
<tr>
<td>Functions</td>
<td>Capacity</td>
<td>Barriers</td>
</tr>
<tr>
<td>Structures</td>
<td>Performance</td>
<td>Facilitators</td>
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</table>
The ICF Model Informs Caregiver Policy

Appreciating caregiver needs on an individualized basis, limitations, activities in the home, community

Understanding risk factors

Appreciating variability in adjustment, feelings over time, positive growth, resilience; depressed, distressed

-Getch chapter

from Kuhlthau chapter
Strategic Training and Support

Recognize CGs as “…experts on the realities of their daily lives”

Strategic use of doctoral-level providers

*McDaniel & Pisani chapter*

Strategic and culturally-sensitive training and education

*Goldsmith chapter, Leung chapter*

Use of home-based interventions

*Elliott & Parker chapter*
Legal and Life Planning Issues

Navigating confusing, contradictory policies, eligibility legal cases e.g., Alberto N http://pcaf.tamu.edu/

Keep caregivers informed of legal issues and implications Bowe chapter

Long-term care and life planning Viola & Arno chapter
A Model for Developing and Sustaining a Comprehensive Care Plan (CP)

Elliott & Parker chapter

Care Recipient

Family Caregiver

Caregiver and Care recipient life course trajectories

The Tasks of Caregiving: Overall Domains

Requirements:

Achieving CP goals requires the sustained, cooperative efforts of the care recipient, family caregivers, other significant caregivers, and a number of trusted professional advisors.

Necessary steps include:

* Understanding of the landscape of caregiving tasks (e.g., medical > locating a medical specialist) associated with a particular condition.
* Completion of initial assessment with health, legal, financial, and spiritual advisors.
* Initiation and completion of all required tasks using state of science and practice resources.
* Identification of high priority tasks
* Ongoing reassessment and task completion as conditions change

Medical

Legal-Financial-Insurance

Familial

Spiritual-Emotional
Summary

Need for informed, comprehensive policies for caregivers

Refine the science base to provide policy-relevant research

Develop contemporary, cost-efficient programs to support caregivers over time and as needed
CANCER CAREGIVING IN THE UNITED STATES

Barry J. Jacobs, Psy.D.
Crozer-Keystone Family Medicine Residency Program—Springfield, PA
www.emotionalsurvivalguide.com
TODAY’S TALK

• The challenges of cancer for seniors
• The challenges of cancer caregiving
• Effective interventions
• The new RCI book
CANCER—A DISEASE OF AGING

• American Cancer Society: 13.7 million US cancer survivors
• (By 2022, 18 million cancer survivors)
• CDC: Over 7 million are 65 or older
Raveis: “Persons aged 5-64 have cancer rates 7 to 16 times higher than younger adults, with rates for persons 65-74 2-3 times higher...The number of cancer patients 65 and older will double in the next 30 years.”
A DISEASE OF AGING (cont.)

CDC:

• **Lung CA**: at age 30, 0.19% of men will contract that disease within 20 years; at age 70, 6.38%

• **Prostate CA**: at age 30, 0.35% of men within 20 years; at age 70, 11.45%

• **Breast CA**: at age 30, 1.89% of women within 20 years; at age 70, 6.08%
DISEASE-SPECIFIC FACTORS AFFECTING CAREGIVING

• Wilkie (right) & Farber: Cancer phases (diagnosis, treatment, survival with monitoring, recurrence, re-treatment and palliative and terminal) pose different challenges to patients and caregivers

• Glajchen (left): Patients have pain (45% in early stages; 75% in advanced stages), fatigue (51-68%), nausea (10-40%), depression/anxiety (25-50%)
TREATMENT-SPECIFIC FACTORS AFFECTING CAREGIVING

- Raveis: Technological advances in cancer detection and treatment have varying effects:
  - Earlier detection leads to higher survival rates but longer periods of time of living with CA
  - Chemotherapy, radiation, surgery have fewer side-effects but still significant adversity
  - More treatments moved from cancer centers to home settings
THE CHALLENGES OF CANCER CAREGIVING

• McCorkle & Given:
• Families experience crisis during CA diagnosis, subsequent treatment and premature death
• CA and its treatments alter family identity, roles, communication patterns, employment and daily functioning
McCorkle & Given

CA caregivers face:

• Increasing number of complex tasks
• High proportion of unmet emotional and physical needs
• Burden (as directly linked to negative caregiving reactions)
CAREGIVING CHALLENGES (cont.)

- Other factors (McCorkle & Given):
  - Spousal caregivers appear to be at particular risk for caregiver distress
  - Caregiver adjustment/distress is correlated with patient’s adjustment/distress
  - Intergenerational caregivers suffer multiple role demands and conflicts; intragenerational caregivers suffer role entrenchment
CAREGIVERS OF LONG-TERM CANCER PATIENTS (Jacobs)

- Mrs. L—69 y.o wife of African-American man with severe chronic nerve pain from chemotherapy following stem cell transplant for multiple myeloma 10 years ago.

- Clinical issues: Husband’s reduced functioning and quality of life detracts from marital quality; loss of income, dreams.

- Wife feels resentful, helpless; withdraws.
LONG-TERM CANCER (cont.)

• Mr. B—80 y.o. Caucasian man with chronic and severe bone pain from metastatic prostate cancer is also the caregiver of his mildly demented wife

• Clinical issues: Worried about wife in event that his current CA recurrence leads to his death; angry at their children for perceived lack of support; markedly depressed
INTERVENTIONS

Baile: Outlines steps toward effective therapeutic alliances between family and professional caregivers, including engaging the caregiver, establishing caregiver role and readiness, providing knowledge and information, and maintaining optimism, as well as promoting problem-solving skills—e.g., PST (Problem-Solving Therapy)
• Includes educational, psychoeducational, support and skill-building strategies (McCorkle & Given)
• Have limited empirical support
• Many programs use multiple components (Glajchen)
• Many family caregivers experience difficulty in obtaining information from physicians and nurses (Glajchen)
IMPLICATIONS FOR FAMILY CAREGIVER SUPPORT PROGRAMS

• Because of complexities of cancer trajectories, treatments and treatment side-effects, family caregivers need ability to effectively navigate the healthcare system and derive crucial information and skills

• AAAs (and others in aging network) should teach about cancer (as they currently teach about dementia)—give CA equal footing

• Foster improved problem-solving
IMPLICATIONS FOR PROGRAMS (cont.)

• Promote focus on quality of life
• Tend family relationships, especially in families contending with cancer as a chronic illness
• Create specific supports for spousal caregivers
• Encourage anticipatory mourning; if necessary, provide later bereavement services
OTHER HIGHLIGHTS OF BOOK

• Talley (right): Had vision to convene expert panels; serves as series editor
• Puchalski: Role of spirituality in lives of caregivers
• Baldwin: Economics of cancer caregiving
• Goodheart: Health disparities in cancer caregiving
Rosalynn Carter Institute: Supporting Caregivers Through Advocacy, Education, Research, and Service

The Online Caregiving Issues and Management Certificate Program

Leisa Easom, PhD, RN
Executive Director
Rosalynn Carter Institute for Caregiving
March 14, 2013
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

• Overview of Presentation
  – Role of the Rosalynn Carter Institute for Caregiving
  – Need for the Caregiving Certificate
  – Skillset of Certificate completers
  – Snapshot of the certificate courses
  – Scholarships/Fellowships available
  – Future plans
Mission and Philosophy
The Rosalynn Carter Institute for Caregiving (RCI) establishes local, state, national, and international partnerships committed to building quality long-term, home and community-based services. RCI has spent over two decades working to accomplish this mission.

Goals and Objectives
The RCI was established in 1987 at Georgia Southwestern State University (GSW) in Americus, Georgia.

The Institute was formed in honor of Former First Lady Rosalynn Carter, an alumna of GSW, to enhance her long-standing commitments to human development, caregiving and mental health through its Advocacy, Service, Research and Education Programs.
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

Needs Assessment Survey

• 400 surveys mailed/ emailed
• Targeted public health, social service, aging services, health care services in southwestern regions of Georgia
• 50% respondents requested certificate as needed for learning and job development
• 66% respondents preferred online format for classes
Certificate Program Need

• Focus on caregiver supports, older adults, and culturally competent care
• Interdisciplinary in nature
• Informs both professionals and family caregivers
• Prepares leaders in the caregiving field
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

Certificate for Academic Credit:

• The “Caregiving Issues and Management” Certificate Program, offered at Georgia Southwestern State University, targets building a comprehensive education program for caregivers at GSW.
• The 18-credit certificate program can be earned as stand alone certificate or in conjunction with a Bachelor’s Degree.
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

Skillset of certificate graduates:
• Analyze a caregiver’s circumstances
• Translate information across healthcare systems and providers
• Assist family caregivers in ID and accessing community and regional services
• Participate actively in interdisciplinary team
• Integrate knowledge and values of caregiving within one’s career field
• Apply knowledge of evidence-based caregiver programs
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

Snapshot of Certificate Courses

• Introduction to Caregiving
• The Caregiving Journey
• Best Practices in Supporting Caregivers
• Theory-Research in Caregiving
• Cross-Cultural and Cross-National Issues
• Advanced Practice Issues in Caregiving
• Special Populations Requiring Care (Approved Substitute Course)
**RCI: Supporting Caregivers through Advocacy, Education, Research, and Service**

**Program Specifics:**

- Online Totally
- Stimulating environment of learning utilizing technology such as video-streaming, discussion, voice-over power points
- All courses stand alone and may be taken in any order
- Evaluations to date reveal high ratings for individual courses and overall program
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

• Admission Requirements: Acceptance at Georgia Southwestern State University
  [http://gsw.edu/Admissions/index](http://gsw.edu/Admissions/index)

• Affordable: flat fee per credit hour – no out of state fees

• Enroll Today!
RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

Thank You.

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RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

Questions?