“Respite: A Vital Element for Caregivers”

16th Annual National Lifespan Respite Conference
October 7-9, 2014

Dr. Leisa Easom
Executive Director
Pope Eminent Scholar
There are only four kinds of people in the world:
Those who have been caregivers
Those who currently are caregivers
Those who will be caregivers
Those who will need caregivers

-Rosalynn Carter
Former First Lady
ABOUT US

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

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.

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.
Over 50 million family caregivers provide the largest proportion of care for dependent elderly individuals as well as adults and children with disabilities and chronic illnesses.
Over 50 million family caregivers provide the largest proportion of care for dependent elderly individuals as well as adults and children with disabilities and chronic illnesses.

Approximately 6,000,000 adults over age 65 need daily assistance to live outside a nursing home today. That will grow to more than 12,000,000 by 2030.
Over 50 million family caregivers provide the largest proportion of care for dependent elderly individuals as well as adults and children with disabilities and chronic illnesses.

Approximately 6,000,000 adults over age 65 need daily assistance to live outside a nursing home today. That will grow to more than 12,000,000 by 2030.

With longer life expectancy, comes higher rates of chronic illness, disability and need for care.
Over 50 million family caregivers provide the largest proportion of care for dependent elderly individuals as well as adults and children with disabilities and chronic illnesses.

Approximately 6,000,000 adults over age 65 need daily assistance to live outside a nursing home today. That will grow to more than 12,000,000 by 2030.

With longer life expectancy, comes higher rates of chronic illness, disability and need for care.

The average senior today will spend two or more of their final years disabled enough to need someone to help with routine activities of daily living because of chronic illness.
AN AGING POPULATION

Figure 1: Number of Persons 65+, 1900 - 2060 (numbers in millions)

- 35 million in 2000
- 36.9 million in 2009
- 79.7 million in 2040
• Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving.
Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving.

Caregiving today is of longer duration, often 5 or more years.
GENERAL ISSUES AND CONCERNS FACING ALL CAREGIVERS

• Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving.
• Caregiving today is of longer duration, often 5 or more years
• Is much more technically and physically demanding.
• Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving.
• Caregiving today is of longer duration, often 5 or more years
• Is much more technically and physically demanding.
• Many caregivers are living with depression.
Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving.

Caregiving today is of longer duration, often 5 or more years

Is much more technically and physically demanding.

Many caregivers are living with depression.

Caregivers have twice the rate of chronic health conditions as opposed to non-caregivers.
ISSUES AND CONCERNS OF SPOUSAL CAREGIVERS

• 1 in 5 caregivers is a spouse, most are older
ISSUES AND CONCERNS OF SPOUSAL CAREGIVERS

- 1 in 5 caregivers is a spouse, most are older
- More likely than non-spousal to provide assistance with medical/nursing tasks such as med. mgmt. and wound care.
ISSUES AND CONCERNS OF SPOUSAL CAREGIVERS

- 1 in 5 caregivers is a spouse, most are older
- More likely than non-spousal to provide assistance with medical/nursing tasks such as med. mgmt. and wound care.
- Less likely to receive support from family and friends.
ISSUES AND CONCERNS OF SPOUSAL CAREGIVERS

- 1 in 5 caregivers is a spouse, most are older
- More likely than non-spousal to provide assistance with medical/nursing tasks such as med. mgmt. and wound care.
- Less likely to receive support from family and friends.
- Less likely to have home visits from health care professionals and aides.
ISSUES AND CONCERNS OF SPOUSAL CAREGIVERS

• 1 in 5 caregivers is a spouse, most are older
• More likely than non-spousal to provide assistance with medical/nursing tasks such as med. mgmt. and wound care.
• Less likely to receive support from family and friends.
• Less likely to have home visits from health care professionals and aides.
• Many spousal caregivers are living with isolation and stress.
68% of Americans believe they can rely on family to meet LTSS needs.
68% of Americans believe they can rely on family to meet LTSS needs.

**Caregiver Support Ratio:**
number of potential caregivers aged 45-64 for each person aged 80 and older.
68% of Americans believe they can rely on family to meet LTSS needs.

**The Growing Care Gap**

**Caregiver Support Ratio:**
number of potential caregivers aged 45-64 for each person aged 80 and older.

2010: 7 potential caregivers for each person in the high risk years of 80-plus
68% of Americans believe they can rely on family to meet LTSS needs.

**THE GROWING CARE GAP**

**Caregiver Support Ratio:** number of potential caregivers aged 45-64 for each person aged 80 and older.

2010: 7 potential caregivers to each person in age 80-plus group

2030: 4 potential caregivers to each person in age 80-plus group
THE GROWING CARE GAP

**Caregiver Support Ratio, United States**

- **Boomers turn 45**
- **Boomers turn 65**
- **Boomers turn 80**

Source: AARP Public Policy Institute calculations based on REMI (Regional Economic Models, Inc.) 2013 baseline demographic projections.

Note: The caregiver support ratio is the ratio of the population aged 45–64 to the population aged 80-plus.
RESPITE: A VITAL ELEMENT

• Caregiving can be like a marathon
RESPITE: A VITAL ELEMENT

- Caregiving can be like a marathon
- Respite provides those essential “stops” or “pauses” to revitalize and refresh
RESPITE: A VITAL ELEMENT

• Caregiving can be like a marathon
• Respite provides those essential “stops” or “pauses” to revitalize and refresh
• Respite can be beneficial, meaningful, and enjoyable for both the caregiver and the care recipient
RESPITE ADVICE FROM OTHER CAREGIVERS

• Let go
RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
RESPITE ADVICE FROM OTHER CAREGIVERS

• Let go
• Learn relaxation techniques
• Maintain a life outside of the caregiving role
RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
- Maintain a life outside of the caregiving role
- Keep a daily “burnout log”
RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
- Maintain a life outside of the caregiving role
- Keep a daily “burnout log”
- Build a caregiving team
RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
- Maintain a life outside of the caregiving role
- Keep a daily “burnout log”
- Build a caregiving team
- Seek spiritual renewal
RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
- Maintain a life outside of the caregiving role
- Keep a daily “burnout log”
- Build a caregiving team
- Seek spiritual renewal
- Appreciate yourself
RESPITE ADVICE FROM OTHER CAREGIVERS

- Let go
- Learn relaxation techniques
- Maintain a life outside of the caregiving role
- Keep a daily “burnout log”
- Build a caregiving team
- Seek spiritual renewal
- Appreciate yourself
- Rely on your sense of humor
VISION
CENTER OF EXCELLENCE FOR CAREGIVING

RCI Training Center

**Evidence-Based**
- Certification/Training
- RCI REACH
- Operation Family Caregiver
- BRI Care Consultation

**Curriculum-Based**
- Caring for You, Caring for Me (facilitator training)
- Educational webinars
- RCI-Korea

Advocacy
- 4 RCI REACH sites (J & J)
- 4 OFC sites (J & J), 3 OFC sites (contract)
- RCI National Summit (J & J)
- Free Caregiver Workshops
- CARE-NET Coalition
- Caregiving Advocate E-Newsletter
- Webinars-Family and Professional
- Presentations to increase caregiving awareness & inform field

Translational Research
- RCI REACH (4 J & J sites, 1 ADSSP site, 1 contract)
- Operation Family CG (4 J & J sites), 3 other
- Care Consultation (1 ADSSP site), 2 contract sites
- Publications/Presentations
- Future collaboration/partnerships
- Online repository of evidence-based and evidence-informed programs
- Metrics to Inform Field

Service
- Caring for You, Caring for Me (caregiver training)
- Phoebe-Sumner Caregiver Support Center
- Pope Scholarships
- Pope Fellowships
- Reaching Out to Assess Dementia (ROAD program)
- Mattie Stepanek Awards
CARE-NET COALITION

• RCI, in the 1990s, developed the CARE-NET (Caregivers Network) program as a unique coalition of caregiver support organizations across a broad array of illnesses and disabilities.
CARE-NET COALITION

• RCI, in the 1990s, developed the CARE-NET (Caregivers Network) program as a unique coalition of caregiver support organizations across a broad array of illnesses and disabilities.

• There are 12 regional CARE-NETs in the coalition throughout the state of Georgia, one in each Area Agency on Aging district.
CARE-NET COALITION

• RCI, in the 1990s, developed the CARE-NET (Caregivers Network) program as a unique coalition of caregiver support organizations across a broad array of illnesses and disabilities.

• There are 12 regional CARE-NETs in the coalition throughout the state of Georgia, one in each Area Agency on Aging district.

• Coalition members include volunteer leaders and advocates from community and state agencies, private corporations, churches and family caregivers who provide ongoing information, assistance, counseling, training and support groups for caregivers throughout Georgia.
The “Caregiving Issues and Management” Certificate Program, offered at Georgia Southwestern State University, targets building a comprehensive education program for caregivers at GSW.
The “Caregiving Issues and Management” Certificate Program, offered at Georgia Southwestern State University, targets building a comprehensive education program for caregivers at GSW.

Total of six courses – all online.
The “Caregiving Issues and Management” Certificate Program, offered at Georgia Southwestern State University, targets building a comprehensive education program for caregivers at GSW.

Total of six courses – all online.

This 18-credit certificate program can be earned as a stand alone certificate or in conjunction with a Bachelor’s Degree.
RCI: SUPPORTING STUDENTS IN CAREGIVING FIELDS

Pope Scholarships.

- Focusing on Caregiving Certificate
RCI: SUPPORTING STUDENTS IN CAREGIVING FIELDS

Pope Scholarships.

- Focusing on Caregiving Certificate

Pope Fellowships

- Opportunities to work directly with caregivers
RCI: SUPPORTING STUDENTS IN CAREGIVING FIELDS

Pope Scholarships.

- Focusing on Caregiving Certificate

Pope Fellowships

- Opportunities to work directly with caregivers

- Monthly meetings with a caregiving focus
OTHER SERVICES/PUBLICATIONS

Networking with State Units on Aging

- Creation of a seamless statewide access to supports for persons with dementia, chronic illnesses and their caregivers
- Georgia: Grant partnership
  - AOA Sustainable Systems - RCI role: Assessment survey, education
  - State wide BRI Care Consultation Roll Out

- Nevada: Grant partnership
  - State wide BRI Care Consultation Roll Out
OTHER SERVICES/PUBLICATIONS

Networking with State Units on Aging

• Creation of a seamless statewide access to supports for persons with dementia, chronic illnesses and their caregivers
• Georgia: Grant partnership
  • AOA Sustainable Systems -RCI role: Assessment survey, education
  • State wide BRI Care Consultation Roll Out
• Nevada: Grant partnership
  • State wide BRI Care Consultation Roll Out

RCI Book Series on Research, Policy, Practice: 9 books

• Education and Support Programs for Caregivers
• Centers for Ending: Crisis in Care of Aged People
• Rural Caregiving in the United States
• Cancer Caregiving
• Caregiving for Alzheimer’s Disease
• Caregiving Across the Lifespan
• Multiple Dimensions of Caregiving
• Challenges of Mental Health Caregiving
• Multidisciplinary Coordinated Caregiving
OTHER SERVICES/PUBLICATIONS

Networking with State Units on Aging
- Creation of a seamless statewide access to supports for persons with dementia, chronic illnesses and their caregivers
- Georgia: Grant partnership
  - AOA Sustainable Systems - RCI role: Assessment survey, education
  - State wide BRI Care Consultation Roll Out
- Nevada: Grant partnership
  - State wide BRI Care Consultation Roll Out

RCI Book Series on Research, Policy, Practice: 9 books
- Education and Support Programs for Caregivers
- Centers for Ending: Crisis in Care of Aged People
- Rural Caregiving in the United States
- Cancer Caregiving
- Caregiving for Alzheimer’s Disease
- Caregiving Across the Lifespan
- Multiple Dimensions of Caregiving
- Challenges of Mental Health Caregiving
- Multidisciplinary Coordinated Caregiving

- A Book About and for Caregivers
- Speaks to Critical Need for Caregiving Respite
THREE EVIDENCE-BASED PROGRAMS
Providing Effective Caregiver Support Offered Through the RCI Training Center of Excellence
BRI CARE CONSULTATION

• Telephonic/Internet
BRI CARE CONSULTATION

- Telephonic/Internet
- **Evidence-based** information and support service for adults with physical and mental health challenges and their family
BRI CARE CONSULTATION

• Telephonic/Internet
• **Evidence-based** information and support service for adults with physical and mental health challenges and their family
• **Personalized** coaching **up to 12 months**
BRI CARE CONSULTATION

- Telephonic/Internet
- Evidence-based information and support service for adults with physical and mental health challenges and their family
- Personalized coaching up to 12 months
- Empowerment to manage care situations
BRI CARE CONSULTATION

- Telephonic/Internet
- Evidence-based information and support service for adults with physical and mental health challenges and their family
- Personalized coaching up to 12 months
- Empowerment to manage care situations
- Tailored to client needs
BRI CARE CONSULTATION

• Telephonic/Internet
• Evidence-based information and support service for adults with physical and mental health challenges and their family
• Personalized coaching up to 12 months
• Empowerment to manage care situations
• Tailored to client needs
• Supportive throughout caregiving journey
BRI CARE CONSULTATION

- Telephonic/Internet
- **Evidence-based** information and support service for adults with physical and mental health challenges and their family
- **Personalized** coaching **up to 12 months**
- **Empowerment** to manage care situations
- **Tailored** to client needs
- **Supportive** throughout caregiving journey
- **Prevents** crisis
BRI CARE CONSULTATION

- Telephonic/Internet
- Evidence-based information and support service for adults with physical and mental health challenges and their family
- Personalized coaching up to 12 months
- Empowerment to manage care situations
- Tailored to client needs
- Supportive throughout caregiving journey
- Prevents crisis

- Benefits: Primary, secondary, and long-distanced caregivers as well as care receivers
BRI CARE CONSULTATION

For individuals, BRI Care Consultation Provides Assistance With:

• Health and Care-Related Information
• Family and Friend Involvement in Care
• Awareness and Use of Community Services
• Coaching Support
BRI CARE CONSULTATION

For individuals, BRI Care Consultation Provides Assistance With:

• Health and Care-Related Information
• Family and Friend Involvement in Care
• Awareness and Use of Community Services
• Coaching Support

For agencies, BRI Care Consultation Provides:
• Computerized Service Delivery System (CCIS)
• In-depth caregiver and care receiver assessment
• Capability to run multiple reports
BRI CARE CONSULTATION

For individuals, BRI Care Consultation Provides Assistance With:

- Health and Care-Related Information
- Family and Friend Involvement in Care
- Awareness and Use of Community Services
- Coaching Support

For agencies, BRI Care Consultation Provides:

- Computerized Service Delivery System (CCIS)
- In-depth caregiver and care receiver assessment
- Capability to run multiple reports

Personal Testimony: “Thanks for all of your concern and knowledge. You have NO IDEA how important it is for me!”

-Care Consultation Caregiver
BRI CARE CONSULTATION

Caregiving Families served: Over 600 in 40 Georgia Counties

*Cost based on Atlanta Regional Commission Care Consultant Salary Plus Fringe Benefits

This project was supported in part by grant number 90AE0349/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services
BRI CARE CONSULTATION

Caregiving Families served:
Over 600 in 40 Georgia Counties

One Care Consultant can effectively serve:
75 to 125 Caregiving Families

*Cost based on Atlanta Regional Commission Care Consultant Salary Plus Fringe Benefits

This project was supported in part by grant number 90AE0349/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services
BRI CARE CONSULTATION

Caregiving Families served:
Over 600 in 40 Georgia Counties

One Care Consultant can effectively serve:
75 to 125 Caregiving Families

Average Annual Cost of Service per Caregiving Family:
$1.03/day or $376.00/year*

*Cost based on Atlanta Regional Commission Care Consultant Salary Plus Fringe Benefits

This project was supported in part by grant number 90AE0349/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services
BRI CARE CONSULTATION RESULTS:
Increased Confidence in Managing Care

Pre
Post

N=439
BRI CARE CONSULTATION RESULTS:
Increased Ability to Organize Family and Friend Helping Network

N=439
BRI CARE CONSULTATION RESULTS:
Increased Ability to Get Respite from Caregiving

N=439
BRI CARE CONSULTATION RESULTS:
Overall Increase In Total Needs Met

N=439
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

• Improved Care
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

• Improved Care

• Reduced Hospital Admissions
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

• Improved Care
• Reduced Hospital Admissions
• Delayed Nursing Home Placement
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

- Improved Care
- Reduced Hospital Admissions
- Delayed Nursing Home Placement
- Fewer Emergency Department Visits
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

- Improved Care
- Reduced Hospital Admissions
- Delayed Nursing Home Placement
- Fewer Emergency Department Visits
- **Decreased** Caregiver Depression and Strain
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

• Improved Care
• Reduced Hospital Admissions
• Delayed Nursing Home Placement
• Fewer Emergency Department Visits
• Decreased Caregiver Depression and Strain
• **Improved** Quality of Life
  – **Reduced** Caregiver Stress and Burnout
  – **Reduced** Relationship Strain
  – **Decreased** Embarrassment and Isolation
BRI REPORTS OTHER BENEFICIAL OUTCOMES IN OTHER RESEARCH STUDIES

• Improved Care
• Reduced Hospital Admissions
• Delayed Nursing Home Placement
• Fewer Emergency Department Visits
• Decreased Caregiver Depression and Strain
• Improved Quality of Life
  – Reduced Caregiver Stress and Burnout
  – Reduced Relationship Strain
  – Decreased Embarrassment and Isolation
• Improved Access to Information
RCI REACH
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

• Face-to-face, intensive
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

• Face-to-face, intensive

• Evidence-based information teaching problem-solving and stress management for families living with Alzheimer’s disease and related dementia
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

• Face-to-face, intensive
• Evidence-based information teaching problem-solving and stress management for families living with Alzheimer’s disease and related dementia
• Six month program delivered in-home
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

• Face-to-face, intensive
• **Evidence-based** information teaching problem-solving and stress management for families living with Alzheimer’s disease and related dementia
• **Six month program** delivered in-home
• **Tailored** to client needs
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

• Face-to-face, intensive
• Evidence-based information teaching problem-solving and stress management for families living with Alzheimer’s disease and related dementia
• Six month program delivered in-home
• Tailored to client needs
• Caregiver Notebook focusing on common issues faced
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

• Face-to-face, intensive
• Evidence-based information teaching problem-solving and stress management for families living with Alzheimer’s disease and related dementia
• Six month program delivered in-home
• Tailored to client needs
• Caregiver Notebook focusing on common issues faced
• Supportive in the caregiving journey
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

• Education about dementia
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

• Education about dementia

• Safety for dementia care recipient
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

- Education about dementia
- Safety for dementia care recipient
- Emotional well being of dementia caregiver
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

• Education about dementia
• Safety for dementia care recipient
• Emotional well being of dementia caregiver
• Health and self-care of dementia caregiver
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

- Education about dementia
- Safety for dementia care recipient
- Emotional well being of dementia caregiver
- Health and self-care of dementia caregiver
- Social support for dyad
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

Six month intervention delivered in up to twelve sessions in the home with the option of three sessions by phone:

• Education about dementia
• Safety for dementia care recipient
• Emotional well being of dementia caregiver
• Health and self-care of dementia caregiver
• Social support for dyad
• Troubling dementia problem behaviors/ caregiver skills.
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

STUDY #1:

Caregiving Families served:
85 in eleven rural Georgia Counties

This project was supported in part by grant number 90AE0320/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

STUDY #1: Caregiving Families served: 85 in eleven rural Georgia Counties

One Care Interventionist can effectively serve: 20 Caregiving Families

This project was supported in part by grant number 90AE0320/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.
RCI REACH: RESOURCES ENHANCING ALZHEIMER’S CAREGIVER HEALTH

STUDY #1:
Caregiving Families served:
85 in eleven rural Georgia Counties

One Care Interventionist can effectively serve:
20 Caregiving Families

Average Cost of Service per Caregiving Family:
$7.00/day

This project was supported in part by grant number 90AE0320/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.
STUDY #2: Caregiving Families served:
121 in Georgia Coastal Region

One Care Interventionist can effectively serve:
20 Caregiving Families

This project was supported in part by grant number 90AE0339/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services.
STUDY II: PRELIMINARY OUTCOMES FOR COASTAL GA REACH PROGRAM

Decreased Burden and Depression

n=121

CG Instruments

Mean Score

Pre
Post

Burden

20.08
20.83

Depression

12.12

Post 13.61

Post 6.99

p value=.000

α= <.05
STUDY II: PRELIMINARY OUTCOMES FOR COASTAL GA REACH PROGRAM

Increase in Physical Health

n=121

Mean Score

Pre | Post
---|---
2.71 | 2.9

p value = 0.051

α = <0.05

CG Instruments
STUDY II: PRELIMINARY OUTCOMES FOR COASTAL GA REACH PROGRAM

Increase in Behavioral Problems and Decrease in Reaction to Behavior Problems

n=121

CG Instruments Mean Score

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td># of Behavioral Problems</td>
<td>28.83</td>
<td>21.3</td>
</tr>
<tr>
<td>Reaction to BP</td>
<td>20.74</td>
<td>1.86</td>
</tr>
</tbody>
</table>

p value = .000

α = <.05
Ready to bring an evidence based caregiver support program to your community?

RCI REACH

Free training and technical assistance funded by ACL!
Apply today!

RCI will provide training, technical assistance and consultation to 20 agencies around the nation.

To learn how to apply:
Email Gayle Alston
Gayle.alston@gswe.edu
OPERATION FAMILY
CAREGIVER:

- Pennsylvania
- New York
- Texas
- California
A program of the Rosalynn Carter Institute for Caregiving, generously funded by Johnson & Johnson
An Evidence Based Caregiver Support Program
Identifying the Need

• Since 2001, 2.4 million active duty and reserve military personnel were deployed to the wars in Iraq and Afghanistan - More than 63,000 service members have been medically evacuated from Iraq or Afghanistan.

• 30% of this group – nearly 730,000 men and women will have a mental health condition requiring treatment.

• 18.5% of all OEF/OIF veterans have post-traumatic stress (PTS) and/or major depression.

• 1 in 6 soldiers returning from deployment have traumatic brain injury.

• Families of service men and women serve and sacrifice. Families are the support system to which the service member returns – they are struggling to cope with resulting depression and frustration.
“When these guys and gals deploy, they come back home with PTSD, TBI, whatever the issue may be - a lot of the spouses I’ve talked to have all said the same thing – they do not know how to deal with their husbands or their wives when they return…their families, whether it’s their wife, their husband, or their children suffer because they’re not prepared for that change…yeah, they get the nice little brief from ACS and the FRG group; ‘your husband is gonna come back changed’, but they aren’t given any tools or resources…for when I didn’t sleep, for when I woke up from the nightmares and I was punching her in her sleep because I didn’t know where I was or what I was doing…”

New Research Findings

- Empower Caregivers
- Create Caregiver-Friendly Environments
- Fill Gaps in Programs
- Plan for Future Caregiving Needs
1.1 million post 9/11 military caregivers who are:

- Younger (more than 40% between 18 and 30)
- Caring for a younger individual with a mental health or substance abuse condition
- Nonwhite
- A veteran of military service
- Employed
- Not connected to a support network (53% lack support)
Most relevant programs and policies serve caregivers only incidentally

- Targeted towards care recipient of military/veteran families
- Most programs limit eligibility to primary family members
- Many programs geared towards caregivers for older populations, younger caregivers not eligible
Caregiving Imposes a Heavy Burden
Post 9/11 military caregivers

- Worse health outcomes
- Greater strains in family relationships
- More workplace problems
- Elevated risk of depression
- 33% lack health care coverage
Why is Military Caregiving Unique?
A new cadre of caregivers…

• Multiple and severe injuries or illnesses
• Complex systems of care
• Invisible wounds
• Around-the-clock care
• A lifetime of care
Problem-Solving Training for Family Caregivers of Persons With Traumatic Brain Injuries: A Randomized Controlled Trial

Patricia A. Rivera, PhD,
Birmingham Veterans Administration Medical Center, Birmingham, AL

Timothy R. Elliott, PhD,
Department of Educational Psychology, Texas A&M University, College Station, TX

Jack W. Berry, PhD, and
Injury Control Research Center, University of Alabama, Birmingham, AL

Joan S. Grant, DSN, RN, CS
University of Alabama School of Nursing, University of Alabama, Birmingham, AL

Abstract

Objective—To test the hypothesis that a problem-solving training program would lower depression, health complaints, and burden, and increase well-being reported by community-residing family caregivers of persons with traumatic brain injuries (TBIs).

Design—Randomized controlled trial.

Setting—General community.

Participants—Of the 180 people who expressed interest in the study, 113 did not meet eligibility
Operation Family Caregiver
Strong Military, Stronger Families

• OFC is a non-clinical, supportive adjunct to any other support the family is receiving.

• A medical or mental health diagnosis is not required.

• Takes basic education a step further to help facilitate behavioral change. This problem-solving, skill-building program prepares the caregiver to be able to handle challenges over the long-term. Caregiver Notebook for each family.
Eligibility criteria
Caregivers and families of OEF/OIF/OND service members/veterans living with Post Traumatic Stress Disorder, Traumatic Brain Injury, and/or a physical disability

OFC is an in-home, tailored, caregiver support intervention:

- 4 in-home visits- face to face or via SKYPE
- Monthly telephone availability
- Data collection at beginning and end
- Program length 4-6 months
- Must complete 75% of sessions to be considered a completer
OFC
Program philosophy

“Give someone a fish and you feed him for a day. Teach someone to fish and you feed him for a life time.”

~ Lao Tzu
Why OFC
Confidential and Free

1. **Evidence-based** (has undergone rigorous scientific evaluation in a randomized control trial)

2. **Proven effectiveness** (has consistently demonstrated the ability to achieve outcomes of importance to family caregivers)

3. **Tailored** to each individual family’s needs

4. **Location** - program comes to the caregiver (their home or other location that caregiver chooses, telephone or Skype)

5. **Minimizes stigma** – a diagnosis of PTSD reflects a mental illness/defect; service members may be wary that seeking help may jeopardize employment or job promotion opportunities; privacy of OFC service setting ensures confidentiality
# Outcomes

## Skill enhancement

<table>
<thead>
<tr>
<th>Training improved caregiver self confidence:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Personal expectations - their goal setting improved once they understood the feasibility of their goals</td>
</tr>
<tr>
<td>• An approach – how to begin working with their loved one</td>
</tr>
<tr>
<td>• Promoting their loved one’s desire for autonomy</td>
</tr>
<tr>
<td>• Better understood the importance of self care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Training caregivers improved knowledge:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Learning more about PTSD/TBI and possible triggers helped equip them to better respond to their loved one</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Desired impact is measurable:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Reduction in caregiver depression</td>
</tr>
<tr>
<td>• Reduction in burden</td>
</tr>
<tr>
<td>• Increase in satisfaction of life</td>
</tr>
<tr>
<td>• Decrease in health issues</td>
</tr>
</tbody>
</table>
OVERALL PRELIMINARY OUTCOMES FOR J & J OFC PROGRAM

Decreased Burden and Depression

n=7

B urden p value = .027
Depression p value = .045

α = < .05
OVERALL PRELIMINARY OUTCOMES FOR J & J OFC PROGRAM

Decreased Health Complaints and Increased Life Satisfaction

n=7

Health Complaints p value=.132
Life Satisfaction p value=.154
\( \alpha = .05 \)
OVERALL PRELIMINARY OUTCOMES FOR J & J OFC PROGRAM

Social Problem Solving: Increased Positive Problem Orientation and Decreased Negative Problem Orientation

n=7

SPSI-R:S Positive p value=.129
SPSI-R:S Negative p value=.281
α= <.05
Joining Forces to Support Military Caregivers

April 11, 2014
Connect with us

Facebook.com/RosalynnCarterInstitute
Twitter.com/RCICaregiving
Linkedin.com/company/the-rosalynn-carter-institute-for-caregiving

Rosalynn Carter Institute for Caregiving
800 GSW Drive
Georgia Southwestern State University
Americus, Georgia 31709-4379
Phone: (229) 928-1234
Fax: (229) 931-2663
Thank You!