BRI Care Consultation and Unmet Respite Needs of Family Caregivers

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**Mission:**

*To advance support for older adults and caregivers*

**National Impact**
- Research and Education
- Evidence-Based Programs
- Community Advocacy

**Local Impact**
- Home and Community-based Services
- Rose Centers for Aging Well
- Margaret Wagner Apartments
- Conference Center
Overview of BRI Care Consultation

Miriam Rose, MEd
BRI Care Consultation

- A telephone-based information and support service for adults with physical and mental health challenges and their family caregivers
- Personalized coaching and advice to empower clients to manage their own care situations
- Ongoing support and assistance throughout the caregiving journey
Issues Prompting Development of BRI Care Consultation

- Fragmentation among services
- Mismatch between professionals’ and consumers’ readiness
- Lack of attention to caregivers
- Difficulty with follow-through by consumers
- Lack of coordination between formal and informal care
- Care situations change, but services are static and short-term
- Too much assessment; too few solutions
- Lack of attention to planning and prevention
How does BRI Care Consultation address these issues?

- Evidence-based method of coordinating healthcare and community services
- Personalized coaching by telephone and computer
- Targets persons with health problems and their caregivers
- Linkages to and monitoring of services
- Facilitates involvement of family and friends
- Ongoing long-term support
Four Types of Assistance

- **Health- and Care-related Information**
  - Empower clients to manage their own situations

- **Family and Friend Involvement in Care**
  - Support and strengthen the informal network

- **Awareness and Use of Community Services**
  - Help clients learn about formal services

- **Coaching and Support**
  - Coach caregiver and provide emotional support
Licensed Sites

There are currently **28** licensed BRI Care Consultation sites in the United States, many of which are managed in partnership with the Rosalynn Carter Institute for Caregiving

*Contact Branka Primetica at bprimetica@benrose.org or 216.373.1662 to schedule a demo and learn about how to become a licensed site*
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.
Key Components

- Initial Assessment
- Action Plan
- Maintenance and Support
Care Consultant as Interventionist

- Knowledgeable professional, experienced with people living with and caring for persons with a chronic condition
- Bachelor’s or advanced degree in social work, nursing, or related field
- Knowledge of coaching, problem-solving, resources
- Excellent communication skills
- Ability to build and maintain relationships via telephone contacts
BRI Care Consultation Implementation in Nevada

Celeste Graham, BS
Overview

I. Introduction
II. Overview of Nevada’s Implementation
III. Care Consultation Information System (CCIS)
IV. Sample Case
V. Benefits
VI. Conclusion
Introduction – Nevada Senior Services

- Non-profit Organization

Mission:
- Community agency providing compassionate care and services to adults and their caregivers, facing challenges of chronic diseases, disabilities, and aging to remain in the community with dignity

- Care Partner Institute

Range of Services:
- Community Based Programs
- Caregiver Support Services
- Southern Nevada Care Connection Resource Center

Who can access Services?
- Senior Adults
- Individuals with Disabilities
- Caregivers
State of Nevada Implementation

- State Demographics
- Implementation
- Successes
- Caseload
- Future Plans
Care Consultation Information System (CCIS)

BRI Care Consultation

Evidence-Based Components:

- Initial Assessment
- Action Plan
- Maintenance and Support
Initial Assessment

- **Domains**
  - “Yes” or “No” screening questions that cover a variety of problem areas for care
  - Planning for the future, arranging services, etc.

- **Detail Questions**
  - Corresponding questions that are asked when a care partner identifies a domain as a problem
Action Plan

A roadmap, charting a path to propel care partners to address their priorities one step at a time

- Developing Goals
  - General statements representing desired change

- Developing Action Steps
  - Small, discrete tasks that gradually address unmet needs
Maintenance and Support

Ongoing Contact
- Maintains support during periods of stability
- Allows clients to provide updates
- Prevents serious concerns

Reassessment
- Re-administering domains and detail questions
- Helps address changing concerns
- Allows for development of new action steps
Case Example – Patrice

- Husband has early stage Alzheimer’s disease
- Caring for her husband for 4 years
- Works full-time
- No formal or informal supports
- Oftentimes feels stressed and overwhelmed
Case Example – Initial Assessment

Domains Triggered

- Arranging Services
- Quality of Informal Supports
- Emotional and Physical Health Strain

Detail Questions

- Finding services to help you when family members are not available?
- Do you have supports in your life?
- Have you had less pep or energy?
### Case Example – Action Steps

#### Domain: Arranging Services
- Contact home modification program at 555-555-5555 to out more information about home safety, such as grab bars
- Follow up with Adult Day Care Center 555-555-4444 to find out hours of operation
- Fill out paperwork for financial assistance programs to help defray cost of Adult Day Care

#### Domain: Quality of Informal Supports
- Reach out to Sally, neighbor/friend, to see if she would be willing to provide respite during the week

#### Domain: Emotional and Physical Health Strain
- Provide educational articles for Patrice to gain insight on ways to reduce frustrations
- Try to go to the gym more each week to attend yoga and spend time with Gary doing other activities
- Each day, find a way to change negative into positive thoughts when thinking about the care situation using the strategies discussed with Celeste, the Care Consultant
Case Example – Maintenance and Support

Reassessment

- Completed at 12 months
- Maintains frequent communication
- Previous concerns have been addressed and maintained
- No other concerns were presented

Domain Update

Arranging Services
- Husband attends Adult Day Care
- Patrice has participated in Alzheimer’s education/caregiver workshops

Quality of Informal Support
- Neighbor assists in transportation and respite

Emotional and Physical Health Strain
- Exercises regularly
- Retired
Program Benefits

- Improved care
- Decreased symptoms of caregiver depression and strain
- Reduced caregiver stress and burnout
- Improved access to information
- Improved quality of life

- “This program keeps me encouraged, it is nice to know I have someone to talk to who is so refreshing and positive.”
- “I am so glad I have people like you to talk to. It makes me feel like I am not alone.”
- “I had no idea I needed to lean on someone like this. Thank you so much for all of your support.”
Conclusion

- Proven to be effective
- Beneficial program for care partners
- Provides caregivers with ongoing support
- Allows care partners to address concerns
- Provides helpful tips and solutions for managing care
- “No Wrong Door”
Live Demo of CCIS Case Record

- Initial Assessment
- Action Plan
- Maintenance and Support
Thank you for your time!

Questions?
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Ohio Partners in Dementia Care

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Studies of BRI Care Consultation

1. Cleveland Alzheimer’s Managed Care Demonstration, 1997-2001
2. Chronic Care Networks for Alzheimer’s Disease, 1998-2004
3. Integrated Care Management, 2005-2007
4. Wellness Network for Older Adults with Depression and Their Caregivers, 2006-2009
5. Partners in Dementia Care for Veterans and their Family Caregivers, 2006-2011
6. BRI Care Consultation in Cleveland, Ohio, 2009-2011
7. BRI Care Consultation in Tennessee, 2009-2012
8. BRI Care Consultation in Georgia Area Agencies on Aging, 2010-2013
9. Ohio Replication of Partners in Dementia Care, 2011-2015
Benefits Found in Research Studies (Evidence Base)

- Improved satisfaction with formal care
- Reduced hospital admissions
- Delayed nursing home placement
- Fewer Emergency Department visits
- Decreased symptoms of caregiver depression and strain
- Reduced caregiver stress and burnout
- Reduced relationship strain
- Decreased embarrassment and isolation
- Improved access to information
Ohio Partners in Dementia Care
VA and Community Organization Partnerships

Benjamin Rose Institute on Aging
(Evaluation and Study Oversight)

Greater Cleveland Veterans and Caregivers

Louis Stokes Cleveland Veterans Administration Medical Center – Wade Park Campus and Cleveland Area Community Based Outpatient Clinics

Western Reserve Area Agency on Aging

Greater Akron and Canton Veterans and Caregivers

Louis Stokes Cleveland Veterans Administration Medical Center – Akron and Canton Area Community Based Outpatient Clinics

Greater East Ohio Area Alzheimer’s Association Chapter
Translational Study

- Utilized Advanced CCIS software
- Effective information sharing across organizations
- Diverse areas - greater Cleveland, Akron, Canton
- Similar outcomes as original controlled trials
- Served Veterans with and without caregivers
- 12-month implementation period
- Funded by Administration for Community Living, Dementia Capable Grant Funding (administered by the Ohio Department on Aging)
Ohio Replication of PDC Study Sample Description

- Research interviews with 200 caregivers of veterans with dementia before and 12 months after enrolling in PDC/BRI Care Consultation
- Sample for analysis of unmet respite need: 148 of these caregivers
  - Average age: 68 (range, 28 – 92); 95% female
  - Ethnicity: 74% white
  - Average caregiving tenure: 6 years (range, 1 month – 65 years)
  - Average age of veterans they care for: 81 (range, 60 – 91); 98% male
Unmet Respite Need Scale

Need more information about or help with: (yes/no)

1. Getting someone to stay with the veteran so he/she would not be left alone
2. Getting a break from care
3. Finding services to provide care when family help is not available
Caregiver Characteristics that Might Predict Unmet Respite Need

- Age
- Ethnicity
- Income
- Share household with veteran
- Satisfaction with help and support from family and friends

- Depression
- Caregiver strain:
  - Emotional health strain
  - Social isolation
- Stressors related to veteran’s characteristics:
  - Need for help with activities of daily living (personal self-maintenance)
  - Cognitive impairment
  - Behavior problems
Caregiver Characteristics Predicting Unmet Respite Need at Baseline

- Age
- Ethnicity
- Income
- Share household with veteran
- Satisfaction with help and support from family and friends

- Depression
- Caregiver strain:
  - Emotional health strain
  - Social isolation
- Stressors related to veteran’s characteristics:
  - Need for help with activities of daily living (personal self-maintenance)
  - Cognitive impairment
  - Behavior problems
Change in Unmet Respite Need

Statistically significant change from

1.6/3 - Average score at baseline
to
1.1/3 - Average score after 12 months in PDC/BRI Care Consultation
Caregiver Characteristics Predicting Decrease in Unmet Respite Need after 12 months in PDC/ BRI Care Consultation

- Age
- Ethnicity
- Income
- Share household with veteran
- Satisfaction with help and support from family and friends

- Depression
- Caregiver strain:
  - Emotional health strain
  - Social isolation
- Stressors related to veteran characteristics:
  - Need for help with activities of daily living (personal self-maintenance)
  - Cognitive impairment
  - Behavior problems
Caregiver Characteristics Predicting Decrease in Unmet Respite Need after 12 months in PDC / BRI Care Consultation

Conclusions:

• Coaching from care consultants enabled caregivers to find solutions to respite needs
• BRI Care Consultation worked well in situations where veterans were more impaired
• Economic resources may facilitate caregivers’ ability to meet respite needs
Thank you for your time!

Questions?
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