State of Caregiving for People with Dementia in Indian Country

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Funded by Administration for Community Living
Grant Number 90OI00302

National Resource Center on Native American Aging

- The NRCNAA is one of three centers that are funded through the Administration for Community Living (ACL/AOA). The other two centers are:
  - The National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (Alaska)
  - National Resource Center for Native Hawaiian Elders (Hawaii)

- NRCNAA established in 1994, at the Center for Rural Health, University of North Dakota School of Medicine and Health Sciences
Administration for Community Living

- **Vision:**
  “All people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society”.

- **Web site:** [http://www.acl.gov](http://www.acl.gov)
NRCNAA MISSION

“Identify and increase awareness of evolving Native elder health and social needs”.

Web site: www.nrcnaa.org

NRCNAAA AIMS

- Empowerment of Native American elder caregivers, elder service providers, and tribal leaders
- Honoring and maintaining cultural values while providing high-quality services
Native Elder Population Projections 1990-2020

CAREGIVING

Alzheimer's Association 2014 Alzheimer's Disease Facts and Figures

- Caregiving: attending to another individual’s health needs
  - Social needs can be part of caregiving

- Typically includes assistance with one or more activities of daily living (ADL’s) and/or instrumental activities of daily living (IADL’s)
Who are the Caregivers

- Typically immediate family and can also be relatives and friends
- 65% are women
- 21% are 65 years of age and older
- 44% have some college education or had earned a college degree
- 64% are currently employed, a student or a homemaker
- 71% are married or in a long-term relationship

Unpaid vs Paid Care

- Large majority of caregiving for people with Alzheimer’s and other dementias is **unpaid care**
  - Over 15 million caregivers provide **unpaid care** for persons with Alzheimer’s and other dementias in America
- Majority of formal care for person’s with Alzheimer’s and other dementias is made up of direct care workers such as nurse aides, home health aides, personal and home-care aides, and nursing assistants. This is the **paid care** caregiving.
Caregiving cost and value

v Unpaid Care
v 15 million caregivers provided 17.7 billions hours of unpaid care
v Those care hours are nationally valued at $220.0 billion
  ✓ Approximately half the net value of Wal-Mart sales in 2012 ($443.9 billion) Wal-Mart 2012 sales report
  ✓ Approximately 8 times the total revenue of McDonald’s in 2012 ($27.6 billion) McDonald’s Corporation Report 2012

CAREGIVERS

Sandwich Generation
v A sandwich generation caregiver is typically a middle-aged person who simultaneously cares for dependent minor children and aging parents.
  ✓ Parents of dependent minors are older than in the past
  ✓ The aging of the US population including American Indian populations growing as life expectancies increase
Caregiver Burden

Burden
“the emotional, psychological, physical, and financial ‘load’ assumed by CG’s, as well as their subjective appraisals of how task performance affects their lives”
(Gaugler et al. 2000:323)

Community & Caregiver Burden

- Tribal communities tend to be in rural areas
- High Unemployment rates and low incomes
- Health care access issues
- Shortage of culturally-competent health providers
- Critical shortage of Long-term services and support which means extensive unmet needs for elders and caregivers
“Identifying Our Needs: A Survey of Elders”

- Assesses elders’ health and social needs
- Run in three year cycles and currently in cycle VI
- Tribes have the opportunity to collect information about their community
- Funded by ACL/AOA for past 20 years

Tribal Participatory Model
Fisher & Ball (2003)

- Tribal Participatory Mechanisms:
  - Tribal Oversight
  - Tribal Resolution
  - Tribal Capacity Building
  - Culturally-Fit Method and Assessment
  - Applicable, Interpretable, and Usable Results
  - Tribal Data Ownership
Purpose of Needs Assessment

- Assists tribes in assessing options and developing an action plan to address local needs.
- Provides documentation required for planning and grant purposes including fulfilling requirements for tribes’ Title VI elder nutrition program grant applications.
- Provides documentation (Family caregivers percentages) to apply for elder caregivers grant applications.

Population

- Native American elders residing primarily on reservations, Alaskan villages and Hawaiian homesteads.
- Individuals age 55 and over living on or around Indian areas.
- Age 55 is considered comparable to 65 and over in the general population
- Data is age adjusted
Tribal Diversity

- NRCNAA’s model addresses diversity between and within tribes:
  - Measures local community needs which are then unique to that community and fit only that particular community.
  - Model utilizes a custom-fitting measure.

One Size Does Not Fit All

Aggregated Representation

- Not a single representative sample of nation’s Native American Elders
  - Represents an aggregation of representative samples from participating tribes
  - Survey and methodology has stayed constant from Cycle II through Cycle V
Regional Variance

- NRCNAA model also addresses regional variance:
  - Such as variance in life expectancy and chronic disease
    - California Indian Health Service Area life expectancy at 76.3 years is close to nations; however, Aberdeen Area is 64.3 a difference of 12 years.
    - Alaska Area has a diabetes rate slightly higher than the general population at 16%; whereas, the majority of other regions area at 37% or more.

The Needs Assessment Survey

- The primary method of data collection is the survey instrument (administered face-to-face with the elders).
- A standardized assessment instrument
  - Surveys provided to the tribes by NRCNAA at no cost.
  - Surveys processed (optical scanner) by NRCNAA at no cost.
  - A copy of the survey can be viewed at [http://ruralhealth.und.edu/projects/nrcnna/pdfs/cycleivsurveyinstrument.pdf](http://ruralhealth.und.edu/projects/nrcnna/pdfs/cycleivsurveyinstrument.pdf)
Survey Needs Data

- General health status of elders
- Indicators of chronic health
- Indicators of visual, hearing, and dental
- Tobacco and alcohol use patterns
- Diet, nutrition, and exercise
- Social support patterns, housing and work
- Health care access
- Unmet needs
- Use and acceptance of services

National Resource Center
Provides:

- Survey instruments – a standardized tool
- Assistance with sampling
- Training on data collection
- Technical support
- Data entry
- Data analysis
- Statistical profiles of your elders
- Comparisons with national norms
Local Communities Provide:

- A resolution from their tribal councils
- A number or count of the elders in the community
- Data collection
- A repository for the findings and are responsible for getting them to the right people
- Local implementation and coordination

Post Data Collection

- NRCNAA receives completed surveys from participating tribes.
  - Surveys are scanned and coded for statistical analysis
  - A data file is created for each tribal participant
  - Standard measures are created (such as Body Mass Index, ADL and IADL limitations, chronic diseases and service uses).
Result Tabulations

- NRCNAA prepares comparison sheets for all participating tribes:
  - Includes each tribe’s data, national data, and data for all Native American elders (tribal aggregate).

- Sample comparison sheet can be seen at: [http://ruralhealth.und.edu/projects/nrcnaa/pdf/comparison.pdf](http://ruralhealth.und.edu/projects/nrcnaa/pdf/comparison.pdf)

- The comparison sheets allow a context for interpretation:
  - Helps to determine whether each tribe’s elders are healthier or less healthy than the norm or whether they have more chronic disease.

Visualizing Disparities

- Data Comparison

Comparisons between our tribe, regions, and the U.S. general population provide documentation of disparities on specific diseases where American Indian people appeared to be at greater risk than others in the nation. This information assists in identifying diseases where health promotion efforts will assist in making significant improvements in health status for our elders. The table on the next slide presents these diseases.
Chronic Disease

The top chronic diseases found among our elders were high blood pressure, arthritis, diabetes, depression and osteoporosis. Each of these lead to limitations on peoples’ ability to take care of themselves. Nutritional care is particularly important for high blood pressure, diabetes and osteoporosis.

Five most common chronic diseases for Our Tribe (persons 55 and over)

<table>
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<th>Region IX</th>
<th>Tribal Agg.</th>
<th>Nation</th>
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<tr>
<td>High blood pressure</td>
<td>60.7%</td>
<td>58.2%</td>
<td>55.2%</td>
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<tr>
<td>Arthritis</td>
<td>44.4%</td>
<td>46.5%</td>
<td>47.4%</td>
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<tr>
<td>Diabetes</td>
<td>45.8%</td>
<td>40.7%</td>
<td>18.0%</td>
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<tr>
<td>Depression</td>
<td>14.1%</td>
<td>14.9%</td>
<td>17.2%</td>
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<td>Osteoporosis</td>
<td>10.5%</td>
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<td>59.4%</td>
<td>52.1%</td>
<td>38.1%</td>
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Visualizing Long-term Services and Support/Unmet Needs

59. Are you now using, or if at some point you became unable to meet your own needs, would you be willing to use the following services? (Please mark all that apply) (Interviewer, please see guide for definitions).

Now Use  Would Use

- Adult Day Care
- Caregiver Program
- Case Management
- Elder Abuse Prevention Programs
- Emergency Response Systems
- Employment Services
- Financial Assistance
- Home Health Services
- Home Repair/Modification
- Information and Referral/Assistance
- Legal Assistance
- Home Delivered Meals
- Congregate Meals
- Personal Care
- Respite Care
- Assisted Living
- Retirement Communities
- Nursing Facilities
- Government Assisted Housing
- Shared Housing
- Senior Center Programs
- Telephone Reassurance
- Transportation
- Volunteer Services
- Long Term Care Services
State of Caregiving

- Loss of Native caregivers
  - Youth more upwardly mobile
  - Students choosing non-tribal community career options
- Higher burden on Native Caregivers
- Respite care being sparse or non-existent for many Native caregivers
- Less training opportunities for caregivers

State of Caregiving
Native Caregiving Strengths

- Reciprocity/Giving back the care
- Resource Sharing
- Collectivism
- Community Cohesiveness
- Resiliency & Survivability
- Adaptability
- Humor
- Respect for Elders
State of Caregiving
Kane (2000)

Native Caregiving Strength

- Native spirituality
- Knowledge base of traditional medicine
- Culturally-unique understanding of psychopathology
- Acceptance associated with caregiving for elders with dementia (less sense of stigma and shame)

NATIVE ELDER CAREGIVER CURRICULUM

Caring for Our Elders
2nd Edition
CARE FOR THE CAREGIVER: RECOMMENDATIONS
NECC Session 3.5

dear stress,
let's break up.

me
THREE MAJOR “RULES” FOR THE CAREGIVER JOURNEY

- Take “one day at a time
- Seek out a supportive listener who will be there for you
- Ask for AND accept help when needed

Service Locator for Native American Elders

The NRCNAA maintains a web-based service locator for Native American elders. Services vary by location, but some examples include help with chores, personal care, home-delivered meals, financial assistance, senior citizens programs and assisted living. You can search by service or by area or both. Please visit us online at http://ruralhealth.und.edu/projects/nrcnnaa/servicelocator.php to check for services available in your area.
Contact Information

For more information contact:

National Resource Center on Native American Aging

Center for Rural Health

School of Medicine and Health Sciences

Grand Forks, ND 58202-9037

Tel: 800-896-7628

Fax: (701) 777-6779

http://www.nrcnnaa.org

References


References


National Alliance for Caregiving and AARP. Caregiving in the U.S. Unpublished data analyzed under contract for the Alzheimer’s Association; 2009.