Addressing Social Isolation and Loneliness Among People Living with Dementia

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Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
Addressing Social Isolation and Loneliness Among People with Dementia

June 25, 2019
Donald R. Smith
Director, Area Agency on Aging of Tarrant County
Vice President, Community Investment
United Way of Tarrant County
Overview

- Older Americans Act Network
- Loneliness, depression and dementia
- Living Alone with Dementia: scope and costs
- Development of targeted programming in Tarrant County, TX
- Future projects and related initiatives
Older Americans Act (OAA) Network

- 56 State Units on Aging
- 600+ Area Agencies on Aging (AAAs)
- 200+ tribal organizations volunteers
- 20,000 service providers
- 50+ year old infrastructure of community-based organizations
- Texas 28 AAAs supported primarily by Title III of OAA
- Area Agency on Aging of Tarrant County, TX (AAATC) part of United Way
Rise of Social Isolation as a Public Health Issue

• Four surveys in past year related to loneliness and social isolation (Cigna, AARP, Kaiser Family Foundation and the University of Michigan)¹

• 33 - 43 percent of older Americans surveyed say they are lonely or always lonely¹

• Severely lonely older adults are at a higher risk for heart disease, dementia, immune dysfunction, functional impairment and early death¹

• National Academy of Science Consensus Study: The Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults (3 meetings)²

• Common progression in AAATC homebound clients: isolation, loneliness, chronic disease, depression, dementia

1. Kaiser Health News: Understanding Loneliness In Older Adults — And Tailoring A Solution
2. National Academies of Sciences Engineering and Medicine: The Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults
Increased Risks of Living Alone

Individuals with dementia who live alone are at an increased risk for:

- Self-neglect
- Inability to manage daily activities and care of themselves
- Medication mismanagement
- Home safety concerns
- Wandering
- Inability to respond to emergencies
- Financial exploitation
- Social isolation and loneliness

3: Identifying and Meeting the Needs of Individuals With Dementia Who Live Alone US Administration on Community Living, Sept. 2015

Area Agency on Aging of Tarrant County
## The Economic Impact of Dementia⁴

<table>
<thead>
<tr>
<th>Source</th>
<th>Individuals Without Alzheimer’s or other dementias</th>
<th>Individuals With Alzheimer’s or other dementias</th>
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</thead>
<tbody>
<tr>
<td>Medicaid</td>
<td>$358</td>
<td>$8,399</td>
</tr>
<tr>
<td>Inpatient Hospital</td>
<td>$3,509</td>
<td>$10,862</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>$749</td>
<td>$15,463</td>
</tr>
<tr>
<td>Skills Nursing Facility</td>
<td>$462</td>
<td>$6,750</td>
</tr>
<tr>
<td>Hospice</td>
<td>$153</td>
<td>$2,017</td>
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<tr>
<td>Home Health Care</td>
<td>$367</td>
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<td>Medicare</td>
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<tr>
<td>Medical Provider</td>
<td>$3,569</td>
<td>$5,792</td>
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<tr>
<td>Prescription Medication</td>
<td>$2947</td>
<td>$3,436</td>
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</tbody>
</table>

⁴Average Annual Per-Person Payments for Health Care & Long-Term Care Services Provided to Medicare Beneficiaries Age 65 or Older, with and without Alzheimer’s or Other Dementias in 2017 Dollars. Alzheimer’s Facts and Figures 2017
Characteristics of Those Living Alone With Dementia

• 26% of those with dementia
• 50% do not have an identifiable caregiver
• 26% more hospital stays than those than living with a caregiver
• 29% more outpatient costs

5: Alzheimer’s Association: 2019 Alzheimer’s Disease Facts and Figures
Tarrant County Demographics

- Total population: $1.9 million (3rd largest Texas County)
- Over 60 population: 350,000+
- Largest cities: Fort Worth (13th largest in US) and Arlington (home of Jerry World)
- 13.3 % of Medicare Beneficiaries diagnosed with Alzheimer’s
Evolution of Dementia Work in Tarrant County

- Community Living Program of Texas (2009-2011)
- Baylor Scott & White, Center for Applied Health Research, Temple, TX
- Resources for Enhancing Alzheimer’s Caregiver Health (REACH II)
- Nutrition, Fall Prevention, HomeMeds and Respite
- Focus on low to moderate cognitive impairment
- Over 90% of high risk remain in community for over 6 months
“Carla, we don’t have any people living alone with Dementia in Tarrant County, do we?”

May, 2016
Goal: Expand the existing dementia-capable system services and supports to increase access to culturally sensitive evidence-based support services to the unserved and underserved population with Alzheimer’s Disease and Related Dementias (ADRD) and their caregivers (CGs).
“I’m more concerned about dementia than anything else right now,” said Don Smith, director of the United Way’s Area Agency on Aging. “We’ve got people living alone with Alzheimer’s and dementia right now.”

There’s a need, Smith said, to integrate medical care with social services.

Fort Worth Star Telegram, March 6, 2017, Bill Hanna: Report outlines Tarrant County’s future healthcare needs. What are they?
“Sometimes we see things that are pretty glaring,” Cook said. “When I was a caseworker, a man invited me into the kitchen and had a paper plate on an electric stove and it was just starting to smoke. I reached over and put the plate in the sink. It was just starting to burn through the paper plate.” In that instance, a call to the man’s daughter took care of the issue …

David Andrews has banned his mom from the kitchen and disconnected the stove. “As long as she can do the three T’s - television, telephone and toilet - we’re good,” David Andrews said. “But that could change tomorrow.”

Fort Worth Star Telegram, March 19, 2017, Bill Hanna: Dementia a ‘difficult process’ for Haltom City woman and her son
Finding People Living Alone with Dementia

• Over half of referrals are from home health agencies and hospitals

• Texas Title IIIC2 Home Delivered Meal Assessment
  
  o Q 26: During the last 2 weeks, on how many days have you had trouble concentrating or making decisions?

  o Q 27: Does the consumer have the ability to make decisions independently?

  o Q 28: Does the consumer appear to have short-term memory impairment?

• Triggers AD-8 for confirmation
MAS Results

- 110 people living alone with ADRD and/or their caregiver received person centered Dementia Options Counseling and were connected with other services
- 43% of caregivers for people living alone were contacted
- 35% of caregivers for people living alone received services
- 342 caregivers received REACH II, Respite or Options Counseling
- 56% of caregivers reported a reduction in burden (Zarit)
MAS Results (continued)

- Culturally and Linguistically Appropriate Services (CLAS) Standards Training

- Services to Black/African American caregivers increased by 11.5%; care recipients by 6%

- Services to Hispanic caregivers increased by 8.4%; care recipients by 2.4%

- The AD8: The Washington University Dementia Screening Test

- AD8 adopted by all partner agencies

- Evolved from single point of access to “no wrong door”
Most Needed Services for People Living Alone with Dementia

• Assisted Transportation
• Personal Care/Attendant Services
• Nutrition/Dietician
• Homemeds/Automatic Medication Aids
• Environmental Safety
• Medic Alert/Safe Return
• Visiting Physicians
• Money Management
Barriers to Serving People Living Alone with Dementia

- Lack of medical diagnosis barrier to access
- Public transportation
- Inflexibility of health care system
- Technology
- Lack of awareness about extent of problem
- Payers unaware of cost to taxpayers
Meals on Wheels of Tarrant County Estimates March, 2019

- 4,156 clients served a year
- 42% (1,746) with Dementia
- 56% (972) living alone with Dementia
- 31.6% (552) have formal diagnoses
Lessons Learned Working with Meals on Wheels (MOW)

The biggest lesson learned is that the Meals on Wheels of Tarrant County is not only an agency who focuses on nutritional meals, friendly visits and safety but has a vast portal and/or database of seniors who live alone with memory decline and/or dementia. As a result of the partnership with MOW, the Area Agency on Aging mostly likely would not have had access to a large number of seniors living alone with dementia without MOW.

The partnership with MOW has created opportunities to share knowledge and strategies between the agencies which has been very valuable. The hope is that this partnership will lead to new opportunities to create potentials program in the future for the older population they serve.

In summary, this partnership has made the Tarrant County strong by collectively using two great agencies to identify those are in need the most.
Outcomes Among Persons Living Alone With Dementia Who Grant Served

Since July 2016, the MAS project has achieved 106.0 % of their overall goal for providing effective services to people with ADRD living alone. (Goal was to serve 100. Served 106 with PCP/Options Counseling.)

Outcome: Since July 2016, 92 persons living along with ADRD (86.8%) have been connected to community resources after completing initial screening and assessment. The MAS project has far exceeded the outcome of serving 30% of people living alone with ADRD and who are connected to community resources.
MAS Focused on People Living Alone (MASPLA)

• Award Date: Extension Grant awarded by ACL in March 2019

• Goal: to prolong safe and independent living in the community for six additional months for 900 people who are living alone with Alzheimer’s Disease/Related Dementia (ADRD)

• Identification: Identify 1500 People Living Alone with ADRD (PLAADRD) using AAA Needs Evaluation and 2060 form

• Screening: in-home dementia screening using AD8 for the 1,500 identified PLAADRD, referral to Dementia Options Counselor with score of 2 or higher

• Serve: 950 clients will receive supportive services including Home Delivered Meals, Nutrition Counseling, HomeMeds, Respite, REACH II, In Home Banking & Money Management, and/or In Home Physician Visits
MAS Focused on People Living Alone (MASPLA)

**GOAL** - to prolong safe and independent living in the community for six additional months for 900 people who are living alone with Alzheimer’s Disease/Related Dementia (ADRD)

**Screening** - in-home dementia screening using AD8 for the 1,500 identified PLAADRD, referral to Dementia Options Counselor with score of 2 or higher MOW

**Identification** - Identify 1,500 People Living Alone with ADRD (PLAADRD) using AAA Needs Evaluation and 2060 form MOW, JPS, ADRC, UNTHSC

**Home Delivered Meals**
- 950 clients receive home delivered meals for 6 months MOW

**Dementia Options Counseling**
- Referral for transition to long term care, if appropriate AAA

**Diabetes/Nutrition Counseling**
- 225 clients receive diabetes/nutrition counseling MOW
- 225 clients receive home meds MOW

**150 Clients**
- Who also score positively in 2 of AD8 items 1, 3, 5, 7 referral to in home physician UNTHSC GAAP

**150 Caregivers**
- Receive services from vendor pool:
  - In-home banking services, money management, exploitation prevention
  - Literacy support services and victim’s services FEPC
  - Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) AANCTC
  - Stress-Busting Program (SBP) for Family Caregivers JLIWAC
  - Powerful Tools for Caregivers (PTC) CCS
  - Savvy Caregiver Program (SCP) AANCTC
  - Respite Care ESNT, AH, RH, JLIWAC

**900 Clients**
- Receive dementia options counseling/referral for Dementia Specialized Support Services (DSSS) AAA

**2-6 on the AD8, low to moderate cognitive impairment, and assessed for Nutrition/diabetes using Nutrition Risk Tool and Diabetes Detection Tool**
Other Related Initiatives in Tarrant County

- Texas Takes on Dementia
- Workforce Education for Healthy Aging and Independent Living (GWEP)
- Direct electronic hospital referrals/Advanced Care Transition Intervention
- Public hospital received Delirium Accreditation
- Dementia Friendly Fort Worth
- Age Friendly Fort Worth
- Health Resource Guide for Caregivers (Three Editions)
- Texas Health Hospital System Social Isolation Project
Acknowledgements

“The MAS & MASPLA grants are supported in part by a cooperative agreement (No. 90AL001801, No. 90FPSG0023) from the Administration on Aging (AoA), Administration for Community Living (ACL), U.S. Department of Health and Human Services (DHHS). Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official AoA, ACL, or DHHS policy.”
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Email: don.smith@unitedwaytarrant.org
Ph: 817-258-8128
Addressing Dementia in the Context of Poverty and Social Isolation

June 25, 2019

Sarah Dulaney, RN, MS, CNS
UCSF Memory and Aging Center
Acknowledgements

- The Care Ecosystem has been developed and implemented with support from the UCSF Medical Center, the Centers for Medicare & Medicaid Services, the National Institute on Aging, and the Administration for Community Living.
Objectives

- Describe lessons learned from implementing the Care Ecosystem at the Curry Senior Center Clinic
- Identify three strategies for optimizing care delivery for persons who live alone with dementia
- Describe two approaches to advance care planning with persons who live alone with dementia
The Care Ecosystem Model

Possin, et al. (2017), Plos Med
Care Protocols

- Referrals
- Intake & Immediate Needs
- Care Plan
- Care Plan Review

Personalized Care Plan Protocols
(default order, adjust as needed)

- Decision Making (Advance Care Planning)
- Referrals & Education
- Caregiver Well-being
- Safety Screen & Recommendations
- Behavior Management
- Medication Reconciliation & Review
About Curry Senior Center

https://www.curryseniorcenter.org/aboutcurry/
Life on the Dirtiest Block in San Francisco

The 300 block of Hyde Street in San Francisco received 2,227 complaints about street and sidewalk cleanliness over the past decade, more than any other.

Jim Wilson/The New York Times

Area of Concentrated Violent Crime & Drug Overdoses

https://discovery.cdph.ca.gov/CDIC/ODdash/

https://www.crimemapping.com/map/ca/sanfrancisco
Tenderloin Neighborhood Demographics

12.5% Population age 65+ in 2016 (8,302)

Race
- 55.7% Asian/Pacific Islander
- 34.7% White
- 5.1% African American
- 3.3% Two or more
- 0.7% Native American
- 0.6% Other

Ethnicity
- 5.8% Hispanic

Image by engin akyurt from Pixabay

https://www.sfhsa.org/about/reports-publications/older-adults-and-people-disabilities
Tenderloin Neighborhood Demographics

- 71% Income <200%PT (poverty threshold)
- 49% Limited English skills
- 49% Living alone
- 12% LGBTQ (age 60+)

[Image](https://www.flickr.com/photos/franciscojgonzalez/8081934431/)

[Link](https://www.sfhsa.org/about/reports-publications/older-adults-and-people-disabilities)
In Spite of Challenges, there is a Sense of Community and Resilience in the Tenderloin

SENIORS AND ADULTS WITH DISABILITIES

Since 1998, Project Open Hand has served nutritious meals - breakfast and lunch - to San Francisco seniors and adults


TNDC’s Tenderloin People’s Garden

San Francisco’s Tenderloin District is one of the only neighborhoods in the city of San Francisco without a full-service grocery store, making access to fresh, affordable food a daily struggle for the many low-income residents of the

http://www.tndc.org/programs/tl-peoples-garden/
Dementia in the Context of Poverty & Social Isolation

- Barriers to accessing medical and social services
- Home & neighborhood safety hazards
- Money & property management concerns
- Lack of advocacy
- Barriers to advance care planning

Image by Leroy Skalstad from Pixabay
Enhance Access to Care and Services

Adaptations to CTN Workflow

- Drop-in appointments
- Home visits
- Facilitate referrals & follow-up tests
- Arrange escort & transportation for appointments
- Medication pill box & prescription delivery
- Meal programs
- Build rapport and trust
- Creative problem-solving
- Try and try again
- Coordinate with medical and social services

Address Safety Hazards

Adaptations to CTN Workflow

- Home modification for falls
- Weapons
- Air quality
- Fire hazards
- Medical ID bracelet
- Infestations
- Spoiled food and other toxins
- Phone and/or emergency alert device
- Monitor, document, report incidents as needed
- Coordinate with medical, social, and legal services to address risks for eviction

Assess Money and Property Management

Adaptations to CTN Workflow

- Assess how bills are paid
- Screen for loss of valuables like house keys
- Screen for theft and exploitation
- Monitor for risk of eviction
- Coordinate with medical, social, and legal services to address concerns

Image by Sabine van Erp from Pixabay

Ongoing Monitoring and Advocacy

Adaptations to CTN Workflow

- Cognition
- Function and activity
- Behavior and mood
- Medications
- Nutrition
- Safety
- Social and professional contacts
- Values and preferences
- Concerns for decision making capacity

Document Advance Care Planning Discussions

Adaptations to CTN Workflow

- Social contacts
  - [http://littlebrothersssf.org](http://littlebrothersssf.org)
  - [https://miraclemessages.org](https://miraclemessages.org)
- Low literacy resources
  - [https://prepareforyourcare.org](https://prepareforyourcare.org)
- Personal narrative
- Observations of daily life
- Relevant past experiences
- Values and preferences

Sudore, et. al. (2018), *JAGS*
Bennick, M., & Lee, T. H. (2019), *JAMA Catalyst*
Cohen, A. B., Wright, M. S., Cooney, L., Jr., & Fried, T. (2015), *JAMA*
Outcome Measures

- Person with dementia
  - Number of medications
  - Depression (GDS-15)
  - Loneliness (UCLA-3)
  - Life Space (6 items)

Image by PublicDomainPictures from Pixabay

Barnes, et.al., (2007), Experimental Aging Research,
Barnes, et.al., (2007), Experimental Aging Research,
**Care Planning Tool**

**Adapted from Southern Maine AAA's Dementia Crisis to Thriving Scale**
## Baseline Data (N = 71) **As of March 2019**

### Person with dementia

<table>
<thead>
<tr>
<th>Relationship to caregiver</th>
<th>Number</th>
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<tr>
<td>Spouse or partner</td>
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<tr>
<td>Parent</td>
<td>6</td>
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<tr>
<td>Other caregiver</td>
<td>10</td>
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<tr>
<td>No caregiver</td>
<td>43</td>
</tr>
<tr>
<td>Missing data</td>
<td>9</td>
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### Race

<table>
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<th>Race</th>
<th>Number</th>
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<tr>
<td>Asian or Asian American</td>
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<td>Black or African American</td>
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<tr>
<td>White</td>
<td>32</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
</tr>
</tbody>
</table>
Medicare billing codes

- Annual Wellness Visit (FQHC G0468)
- Complex Chronic Care Management (99490, 99487, 99489), (FQHC G0511)
- Cognitive Assessment and Care Planning (99483)
Key Points

- Increase access to care & services
  - Drop-in appointments
  - Home visits
  - Escorts & transportation
  - Reduce burden of eligibility & enrollment processes
  - Build rapport and trust
  - Advocate

- Engage in advance care planning discussions
  - Identify social contacts
  - Use personal narrative to help understand values and preferences
  - Document conversations, as well as forms if possible
For More Information:
Care Ecosystem Website, Toolkit, and Training Videos

https://memory.ucsf.edu/care-ecosystem

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