



MEETING THE CHALLENGES OF  
DEMENTIA IN NEW MEXICO  
NASW-NM CONFERENCE  
MARCH 7, 2019

BEST DEMENTIA CARE PRACTICE-  
MOBILIZING SOCIAL WORKERS

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SOCIAL WORK PRACTICE AND DEMENTIA  
CARE- A CALL FOR ACTION

- The symptoms of Alzheimer's disease includes difficulties with memory, language, problem solving and other cognitive skills that affect a person's ability to perform everyday activities.
- Social workers are frequently the first responders in situations that require assessment of an individual's capacity for decision-making and self-care.
- Almost 2/3 of Americans with Alzheimer's are women and in addition to gender differences, Alzheimer's dementia affects racial and ethnic groups disproportionately.

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HEALTH DISPARITIES IN PEOPLE LIVING  
WITH AND AT RISK FOR DEMENTIA

- In an interesting webinar sponsored by the National Alzheimer's and Dementia Resource Center and the Administration for Community Living, highlights of the Minority Aging Research Study (MARS) and United Family Caregivers efforts in Milwaukee County, Wisconsin, revealed the need for culturally competent interventions.

Minority Aging Research Study (MARS)-Alzheimer's Association: Alzheimer's & Dementia, 6(2015); Hernandez et al., 2010  
United Family Caregivers-Supporting African American Caregivers in Milwaukee County, Garr, Andrea (7/26/2018)

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### DISPARITIES FOR MINORITY POPULATIONS



- African Americans are about 2 times more likely than whites/Caucasians to have Alzheimer's Disease, but, 40 % less likely to receive anti-dementia medications.
- Risk factors appear to show race differences in the risk of decline such as social engagement, early life diversity and physical activity. Also there is an increase in the risk for cognitive decline from factors that influence this such as distress proneness and neighborhood social disorder.
- Discrimination is an important psychosocial stressor with links to adverse health outcomes and it partially explains disparities in health. Individuals with higher perceived discrimination scores performed worse on cognitive tests.
- The context of one's life influences cognitive functioning as the degree to which a person finds their lives unpredictable, uncontrollable, and overwhelming.

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### MINORITY POPULATION DIFFERENCES

- Less likely to have a formal diagnosis
- Higher level of stigma attached to dementia
- Less informed about dementia, the risk factors and the community resources available to help
- Less likely to access resources, services and supports to reduce caregiver stress and improve well-being
- Fear and distrust of health care systems and interventions due to history of abusive practices
- Cultural differences in beliefs, values and expectations around caregiving (for example, honoring elders, making sacrifices and "giving back," respect, privacy, pride and self-sufficiency).



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### INTERVENTION MODELS AT THE UNITED FAMILY CAREGIVERS PROJECT

- Different intervention models were used:
  - Memory Care Connections, Dr. Mary Middleton Model of NYU
  - United Community Center, adapted from IMPACT model, employing behavioral stimulation and problem solving.
- Friendly Visitor
- Music and Memory
- Respite



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BEST SOCIAL WORK PRACTICE	
<ul style="list-style-type: none"> <li>6 Core Values of the National Association of Social Work (NASW) Code of Ethics:</li> </ul>	
Service	Providing help, resources, & benefits so people achieve their max potential.
Social Justice	Upholding the condition that in a perfect world, individuals would have identical rights, protection, support for obligations & social benefits.
Dignity and Worth of Person	Holding in high esteem & appreciating every individual value
Importance of Human Relationships	Valuing the interactions between social worker & clients, including how they communicate, think, behave towards one another
Integrity	Maintaining trustworthiness & sound adherence to ideals
Competence	Having the necessary skills and abilities to work with all client needs

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**2018 DEMENTIA CARE PRACTICE RECOMMENDATIONS**

alzheimer's association

From: Alzheimer's Association Dementia Care Practice Recommendations  
Gerontologist. 2018;58(suppl\_1):S1-S9. doi:10.1093/geront/gnx182  
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**SOCIAL WORK PRACTICE IN DEMENTIA CARE RECOMMENDATIONS**

- Along the wheel of best practice, social workers are key in the assessment component and helping with care planning.
- Often, social workers play a critical role in helping individuals who support those with cognitive decline, but, do not self-identify as family care givers and assisting in helping with naming their roles.
- Validation of the caregiving role is helpful in identifying and accessing supports, both to care for their family members and to maintain their own wellness.
- Social workers may be involved in performing regular, comprehensive person-centered assessments and timely interim assessments.
- Assessment serves as an opportunity for information gathering, relationship-building, education and support.
- Social workers can serve to bridge the knowledge of and referrals for a variety of resources aimed at supporting individuals and their families facing challenges of dementia.

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**IMPORTANT CONSIDERATIONS FOR SOCIAL WORKERS TO KNOW**

- Understanding of the caregiver's experience.
- The importance of establishing relationship & building trust.
- Cultural values and long term care.
- Active listening and observation about concerns around cognition , signs and symptoms of cognitive impairment, noting changes in cognition that occur abruptly or slowly over time.
- Approaching assessment & care planning with a collaborative, team approach.
- Encouragement for advance planning to optimize physical, psychosocial, and fiscal well-being and to increase awareness of all care options.

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**CAREGIVERS' EXPERIENCE**



- Reasons for not reaching out for help (sooner):
  - Lack of awareness about what community supports are out there and how to access them;
  - Lack of awareness about dementia as a neurological disorder and not part of "normal aging";
  - Privacy – do not want anyone else to know (don't put business in the "street");
  - Wanting to honor their elders. Providing care is seen as a way of expressing gratitude for the sacrifices the elders made on one's behalf;
  - Respect- a desire to have the "permission" or "consent" of the care recipient before the caregiver accesses a community resource;
  - A belief that the care demands can be and are best handled on their own.
  - A belief that the resources are "not for us."

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**ESTABLISHING RELATIONSHIP & BUILDING TRUST**

- Be authentic!
- People are influenced and/or motivated based upon "relationship"
- Do not assume that you know better than your client does about what is needed. When it comes to *their* situation, they are the expert!
- **Ask** what services/supports would be most meaningful to the caregiver/family. Help make the connections between the intervention and the caregiver's stated needs, goals and preferences.
- Do not just "tell" someone what they need to do. If possible, journey "with" them.
- Do not make assumptions about financial resources or priorities.
- Do not make any assumptions. Ask! Then *listen*.
- Be humble, open and prepared to learn from those you serve. Serving others is often a reciprocal relationship.

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**A FEW CULTURAL ASPECTS PERTAINING TO CAREGIVING**



- Caregiving at times can be a "family affair." There can often be two or more "primary caregivers" sharing the responsibilities of care.
- It is not uncommon to include several family members, including the person with dementia, in the decision-making process.
- Avoid using terminology such as "respite," "caregiver burden" and "placement." Instead, discuss these concepts using terms such as "help" or "break," "stress" and "planning for when a loved one's care demands exceed what can be safely provided at home."
- Out of home placement is not for everyone nor every family. Help caregivers create care plans, and contingency plans, that honor their choices, preferences and values and meet their loved one's increasing care requirements within available resources.

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**RESOURCES & GUIDING REFERENCES FOR SOCIAL WORKERS**



- NASW Standards for Social Work Practice with Family Caregivers of Older Adults (2010)
- NASW Standards and Indicators for Cultural Competence in Social Work Practice (2015)
- "A Guide to Quality Care from the Perspectives of People Living with Dementia" (1/2018, Alzheimer's Association)
- Alzheimer's Association Dementia Care Practice Recommendations (published in *The Gerontologist*, 2018, Vol. 58, No. S1, S1-S9)
- *Empowering Social Workers for Practice with Vulnerable Older Adults*, Barbara Soniat and Monica Melady Micklos, 2010, NASW Press
- *A Guide for Caregiving: What's Next? Planning for Safety, Quality and Compassionate Care for Your Loved One and Yourself*, Tina Marrelli, RN, Marrelli & Associates, Inc. Publisher, 2017)
- *Taking Care of Aging Family Members: A Practical Guide*, Wendy Lustbader & Nancy Hooyman, Revised Edition, Simon & Schuster Publishers, 1994

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