Live Well at Home: Engaging African American and Hmong Caregivers

The goal of this Live Well at Home grant, received from the MN Department of Human Services, was to respond to the increasingly racially and ethnically diverse population of older adults, and the need to support caregivers, by developing and testing an initiative related to meeting the needs of caregivers in the African American and Hmong communities. This summary of basic concepts, barriers, and opportunities to engage caregivers is based on a review of recent studies and current research about caregivers from communities of color, combined with information shared by representatives of African American and Hmong communities.

Caregiving background

- Caregivers experience anxiety and stress from caregiving responsibilities. A gradual increase in responsibilities can occur before caregivers realize the toll on their health and other aspects of their lives.
- Caregivers feel a deep sense of responsibility for their care recipients' welfare, and frequently make significant personal sacrifices of their own time and resources to ensure that care recipients' needs are met. The use of any service by a caregiver is frequently weighed in terms of how it will benefit their care recipient.
- Help from family, friends, and other individuals is the most important source of social, emotional, and (often) instrumental support for all groups.
- The use of formal supportive services by all caregivers is influenced by unique cultural values, group identity, and service barriers. However, since most services, including caregiver services, are designed and delivered by the majority population, the services may not feel appropriate or comfortable to those who are part of non-majority populations.

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Common barriers to service use

- Cultural traditions regarding family obligations for care of elders guide much of the Hmong and African American caregiving experience. Caregiving is not usually seen as a distinct or separate role, and it is often a fundamental expectation that is fulfilled without question. Cultural traditions may be harder to maintain among younger generations. In particular, Hmong caregivers do not typically self-identify as caregivers.

- Supports that meet cultural needs, including native languages for immigrant populations and culturally relevant materials are important. Caregivers are more comfortable with connections that occur within their ethnic communities, and in their native languages.

- A lack of full information about what services and supports are available, and difficulty finding sources of useful information in the immediate community create barriers. Younger caregivers may be more tech savvy and able to use on-line information sources.

- Mistrust of established systems in the dominant culture, and reluctance to share personal information and stories keep people from accessing services.

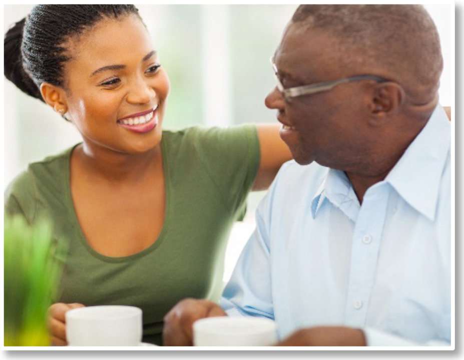
- Lower health literacy may make it more difficult for caregivers to navigate complex social service systems and leverage resources in the system. Cultural beliefs about health care may influence connections and access to services.

- Concerns about the quality of services such as in-home respite, help with household tasks and personal care services, and misgivings about having unfamiliar people come into their homes keep caregivers from seeking services.

- Cost of services, especially those associated with respite, home health, housekeeping, and transportation services create obstacles to accessing services. Concerns about how using one service may affect other public assistance may also delay access. The need for providing or arranging for transportation is a burden.

- Caregivers may fail to recognize the need for help while managing the daily and pressing responsibilities of caregiving. Many caregivers do not plan to use additional formal supportive services until they see no other option, choosing instead to rely on informal support from family, friends, and non-relatives.

Opportunities for engaging and supporting caregivers



- Provide easy access to information about caregiving services and supports in specific cultural communities, including accurate information in a variety of formats and in multiple languages. Information needs to be responsive to caregivers' specific needs at that time.
- Offer in-home and community-based services that are flexible, trustworthy, and affordable, including those that are available according to a sliding fee scale.
- Provide in-home and community-based services that are provided by staff from the same cultural community, relevant to their cultural norms and practices (e.g., emphasize a family-centered approach), and presented in culturally familiar ways. Expand existing efforts to provide more public funding to agencies delivering culturally specific services.
- Deliver in-home and community-based services that help caregivers put the needs of their care recipients first, and offer practical assistance (such as help with paperwork and translations). Once connected to a service, many use this connection as a pathway for getting information and for links to additional assistance.
- Increase opportunities to connect with health care providers, members of faith communities, friends and family members, and other trusted informal sources to gain culturally relevant support and information. Each potential interaction is an opportunity for information to be exchanged, needs to be assessed, and support to be provided. This would require expanded education to community and health care providers about how caregiver supports can be accessed and who can deliver them in a culturally appropriate way.
- Provide opportunities for connections in intergenerational settings within the Hmong community in order to raise awareness of caregiving within younger generations; provide opportunities for connections in faith communities within the African American community.
- Foster partnerships that strengthen the existing capacity and resources of the cultural communities. Building relationships takes time and patience.

References

Alzheimer's Association. *Serving African American families: Home and community based services for people with dementia and their caregivers.* Retrieved from http://www.alz.org/national/documents/aoagrant_kts_aa.pdf

Brookman, C., Holyoke, P., Toscan, J., Bender, D., & Tapping, E. (2011). *Promising practices and indicators for caregiver education and support programs*. Markham, ON: Saint Elizabeth Research Department.

Casado, B. L., van Vulpen, K. S., & Davis, S. L. (2011). Unmet needs for home and community-based services among frail older Americans and their caregivers. *Journal of Aging and Health*, *23*(3), 529–553.

Friedemann, M-L, Newman, F.L., Buckwalter, K.C. & Montgomery, R.J.V. (2014). Resource need and use of multiethnic caregivers of elders in their homes. *Journal of Advanced Nursing, 70*(3), 662-673.

Herrera, A. P., George, R., Angel, J. L., Markides, K., & Torres-Gil, F. (2013). Variation in Older Americans Act caregiver service use, unmet hours of care, and independence among Hispanics, African Americans, and Whites. *Home Health Care Services Quarterly*, *32*(1), 35–56.

Hong, S.-I. (2010). Understanding patterns of service utilization among informal caregivers of community older adults. *Gerontologist*, *50*(1), 87–99.

Mather, M., Jacobsen, L.A. & Pollard, K.M. (2015). Aging in the United States. *Population Bulletin, 70 (2)*.

Montoro-Rodriguez, J., Kosloski,K., & Montgomery, R.J.V. (2003). Evaluating a practice-oriented model to increase the use of respite services among minorities and rural caregivers. *The Gerontologist, 43*(6), 916-924.

Nápoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease and Other Dementias*, *25*(5), 389–406.

National Academy of Sciences. (2016). *Families caring for an aging America*. Retrieved from http://nationalacademies.org/hmd/reports/2016/families-caring-for-an-aging-america.aspx

Pinquart, M. & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist, 45(1)*: 90-106.

Reinhard, S.C. & Choula, R. (2012). *Meeting the needs of diverse family caregivers* (Insight on the Issues No.69). AARP Public Policy Institute.

Scharlach, A., Kellam, R., Ong, N., Goldstein, C. & Fox, P. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work, 47(1-2),* 133-156.

Wennberg, A., Dye, C., Streetman-Loy, B., & Hiep Pham. (2015). Alzheimer's patient familial caregivers: A review of burden and interventions. *Health & Social Work*, *40*(4), e162–e169.

Wilder Research. (2012) *Caregiving in context: Understanding caregivers' networks of support*. St. Paul, MN.

Wilder Research. (2013). *Caregivers to older adults: How they connect to services and how connections can be encouraged and strengthened.* St. Paul, MN.

Wilder Research. (2017). *A study of Title III-E Caregiver Services in Minnesota: Where are we now and where could we go next?,* St. Paul, MN.

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For more information

For more information about this summary, contact Christin Lindberg at Wilder Research, 651-280-2728.

Author: Christin Lindberg

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