Supported in part by a cooperative agreement No. 90AL0011-01-00 from the Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. 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. The grant was awarded to University of Hawaii Center on Aging for the Alzheimer’s Disease Initiative: Specialized Supportive Services Program.
Dementia and the Role of Culture in Care Practice

Dr. Colette Browne
University of Hawai`i
March 2016
Acknowledgements

- Dr. Christy Nishita, Dr. Ritabelle Fernandes, and Ms. Jody Mishan
- Our guest consultants Michele Barclay and Dr. Terry Barclay and other speakers
- Community Experts and Conference Attendees –

Mahalo
Session Format

- **Dementia, Culture and Caregiving**
  - Findings: What do we Know and NOT know?
  - The Concept of Singularity of Place
  - Social and Health Disparities, Culture Competence, Culture Tailoring, and Culture Based Programming: What Can we Learn from other Health Issues?
  - Some Practice Implications and Conclusions
  - References
Key Themes

WHAT DO WE KNOW? WHAT DO WE NOT KNOW?
What We Know: The Good News

- Greater longevity—lucky we live Hawai`i
- Many adults experience good health in their later years
- Hawai`i has many family caregivers who provide an enormous amount of care to their relatives and friends who need their support
- Current population projections point to an increasing growth in the number of older Hawai`i residents including Native Hawaiians in Hawai`i
What We May Not Know: Challenges

- Some populations (i.e., Native Hawaiians, Filipinos) face excess burden of health disparities – does this translate to dementia prevalence?
- Extended longevity will lead to soaring demand for LTSS provided in various settings.
- Reliance on family caregivers may no longer be sustainable.
- **Numbers of older adults with some type of dementia will grow and further tax families and institutions.**
- Present LTSS system not affordable, and expansion of Medicaid to cover the gap group is not forthcoming.
- Limited data on cultural dimensions of dementia caregiving.
Culture and Health Matter

• Racial/ethnic and cultural group variations in views of health and disease in symptom manifestation and diagnosis and preferred help seeking and treatments

• Psychosocial interventions for an ethnically diverse must take into account cultural values, beliefs, traditions and histories of oppression if they are to reach:
  • Better health
  • Improved access to care
  • Lower levels of caregiver burden and
  • Other desired outcomes

The Concept of Singularity of Place

Hawai`i and Cultural Values
What would Marcus say?
Cultural Iceberg

Cultural Competence

- A group’s values, beliefs, traditions and histories influence how a health issue is defined, how care preferences are chosen, and certain services are accessed.
- The responsibility of professionals and other care providers to incorporate this information into their practice.
- A strategy to alleviate health disparities.
Turning the Cultural Lens “In”

Cultural competence—requires examination of our own culture and beliefs about family, caregiving, dependencies, age and older adults and what is the “right thing to do” when frailty occurs.

Cultural humility—requires that we incorporate the habit of self critique and reflection and life-long education in our work with others.

Stanford Geriatric Education Center
Social and Health Disparities

• Social determinants of health result in disproportionate risks for poor health

• Despite some progress, persistence of documented social and health differences in morbidity and mortality outcomes by race, ethnicity, gender, and other variables
Cultural Competence, Culture Based Programs, and Common Goals to Alleviate Disparities:

• Improve health and longevity

• Improve access to interventions—remove barriers to care

• Develop/test culture-based programs to make them acceptable and utilized

• Train staff in cultural knowledge and sensitivities
TRANSLATING CULTURAL COMPETENCE TO PRACTICE:
CULTURE TAILORED AND CULTURE BASED CARE
# Universal and Culturally Specific LTSS Needs

<table>
<thead>
<tr>
<th>Universal</th>
<th>Culturally Specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Financial assistance</td>
<td>• Programs/services that reflect cultural values, communication styles, etc.</td>
</tr>
<tr>
<td>• Respite care</td>
<td>• Respectful providers “of” the culture and/or have knowledge of the culture and its history</td>
</tr>
<tr>
<td>• Family education on health issues</td>
<td>• Services that earn trust; e.g., available in all communities, linguistic literacy</td>
</tr>
<tr>
<td>• Elder/family education on resources and how to access them</td>
<td></td>
</tr>
<tr>
<td>• Home and community-based services, but also residential when needed</td>
<td></td>
</tr>
</tbody>
</table>
Culture based Programming: What Have We Learned?

- Culture-based programming aims to address social and health disparities and culturally specific needs/preferences

- Has achieved success with other health issues--cancer, smoking cessation, diabetes and heart disease.

- Emphasizes respectful attitudes to different approaches to research and knowledge development (e.g., CBPR), and honoring indigenous and diverse knowledge and history

- Good results and outcomes—importance of culture in customizing evidence based models and interventions based on diverse values, traditions, histories and present day realities of populations.
Culture Tailored? Culture Based?

• Adapts a “best” or evidence based practice to be more “in tune”, sensitive or respectful of another group’s culture, traditions, etc. Example: Stanford Chronic Disease Self Management Program (Tomioka et al., 2011)

• Built “from” the culture, acknowledges the cultural and historical strengths of a population or group. Example: The Hula and Hypertension Study (Kaholokula et al., 2015)
Translating Culture Based Programming to Dementia Practice

• To-date, very limited research

• Implicit specific cultural practices grounded in individual and group's particular preferred approaches

• Importance of family engagement but also “every day” realities and complexities of culture AND dementia care

• Desire for respectful and knowledgeable care by providers; e.g., culture Iceberg, health equity framework [resiliencies and adversities]

• Acknowledge and address Issues of trust and mistrust and perceived discrimination
Case Example: Native Hawaiians Health and Social Disparities

- Shorter life expectancies compared to other major r/e groups in Hawai`i
- Higher cancer death rates than non-Hispanic Whites
- 5-year relative survival rate for all cancers for NHs is lower than other r/e populations
- Age-adjusted prevalence of diabetes 3 X greater compared to non-Hispanic whites
- Higher rates of smoking alcohol consumption, and obesity
- Increased likelihood elders live with families—rarely use LTSS
Dementia in Native Hawaiians

- Good news/bad news—living longer but now face emerging issue of the dementias
- Health profile places NHs at high risk for dementia
- No large scale prevalence dementia studies
- CT/CB programs with other health concerns produce positive health results; i.e., increased access, improved health
- Need to test CT/CB approaches in dementia care & target specific health factors & behaviors to reduce incidence
A recent study of kūpuna and `ohana caregivers:
(Browne, Mokuau, Ka`opua, Kim, & Braun, 2014)

- Strong respect for elders
- Age equated with wisdom and traditions, not decline
- Importance of spirituality as a coping mechanism
- Family and community focus
- Values of *aloha, `ohana, pono*
- Preferences for S & P staffed by those from their communities and/or knowledgeable of their community
Practice Findings—Recognizing:

• Some needs are universal; others are not

• Importance of assessment of cultural values and traditional ways, knowledge of history, and impact of discrimination on service design and delivery with diverse populations

• Need for [all] staff training on diversities and culture

• Identifying preferred approaches (e.g., family rather than individual education).

• Work closely with other community based initiatives for design and dissemination efforts
Culture and Dementia Care: Conclusions

- Increasing racially/ethnically diverse State kūpuna population

- Greatest longevity of all 50 states but health disparities persist, some more at risk for dementia than others.

- Many cultural barriers to assess for and cross (socially constructed meaning of aging and AD, fear of social stigma, actual/perceived discrimination in accessing services, ways of coping, family structure)

- Great need for accessible/affordable LTSS for elders and family

- **Extend the testing of Culturally-Based LTSS to dementia care.**

- Providers educated and sensitive to practice implications around the complexities of dementia and culture practice
Suggested Resources


- Health professionals: Get #Alzheimers and #dementia tools and resources for your practice. [https://t.co/xjXbgjCXiU](https://t.co/xjXbgjCXiU)


Questions... and Mahalo!

For additional information, please contact: Dr. Colette Browne, Myron B. Thompson School of Social Work, University of Hawai`i at cbrowne@hawaii.edu.