Caring for our Kūpuna and Families

Dementia and the Role of Culture in Care Practice

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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
- Practice Implications and Conclusions
- References
WHAT DO WE KNOW? WHAT DO WE NOT KNOW?
Greater longevity—lucky we live in multicultural Hawai`i!

Many older adults experience good health in their later years and yet advanced age is the greatest risk factor for dementia

Family caregivers in Hawai`i provide an enormous amount of care to their relatives and friends who need their support including those with dementia

Current population projections point to an increasing growth in the number of older Hawai`i residents including Native Hawaiians, the indigenous people of Hawai`i
What We May Not Know: Our Challenges

- Some populations (i.e., Native Hawaiians, Filipinos) face excess burden of health disparities – does this translate to dementia prevalence? It may…..

- Extended longevity will lead to soaring demand for LTSS provided in various settings

- Reliance on family caregivers may no longer be sustainable due to economic and other challenges

- 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 care preferences and caregiving
CULTURE

• Comprised of beliefs about reality, how people should interact with each other, what they know about the world, and how they should respond to the social and material environments in which they find themselves.

• Reflected in how people and groups see themselves, and their religion, spirituality, morals, customs, politics, technologies, and survival strategies. Culture affects how individuals and groups work, parent, love, marry, and understand health, mental health, wellness, illness, disability, and end of life.

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 discrimination and 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

Going Beyond the “tip” of the Iceberg
Cultural Competence

- Strategies to alleviate health disparities—from individual, community, institutional, organizational, and political responses; e.g., language literacy, staff training, programs accessible to all elders and all neighborhoods

- Based on how a group’s values, beliefs, traditions and histories influence the ways in which a health issue is defined, how care preferences are chosen, and how certain services are accessed
Cultural Competence: Turning the Cultural Lens “In”

You—are a cultural being with your own beliefs that may or may not be shared with and by others

Cultural competence—requires examination of our own culture and beliefs about family, caregiving, 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.

Person Centered Care—requires the culture of both the elder and service provider be considered in seeking the best solution to a dementia-related challenge

Stanford Geriatric Education Center
Cultural Competence and Examples of Goals to Alleviate Disparities:

• Improve health, longevity and general well-being

• Improve access to interventions—remove barriers to care

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

• Educate myself and train staff in cultural knowledge and sensitivities
Translating Cultural Competence to Practice:

Culture tailored and culture based care
Universal and Culturally Specific LTSS Needs

Universal Needs
• Financial assistance
• Respite care
• Family education on health issues
• Elder/family education on resources and how to access them
• Home, community-based, and residential care/services

Culturally Specific Needs
• Programs/services that reflect cultural values, preferred foods, communication styles, etc.
• Respectful providers “of” the culture or have knowledge of the culture
• Services that “earn” trust; e.g., available in all communities, i.e., linguistic literacy
Culture-based programming aims to address social and health disparities and culturally specific needs/preferences.

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 of a people.

To date: positive results and outcomes—but limited in dementia care.
Two Approaches to Cultural Competent Programming:

**Culture Tailored**

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

**Culture Based**

- 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)
The Ola Hou Study: Addressing Disparities with Hula, the Traditional Hawaiian Dance

• 12 week community-based hypertension management program--JABSOM
  1 hour group hula class, 2 X week
  3 hours culturally tailored heart health education
• 27 Intervention, 28 control well matched (Look, Seto, deSilva, Usagawa, Kaholokula 2013)
Program Description and Key Findings

• Establish aloha as a class expectation
• Circle Sharing
• Walking, dancing, walk-sing cool down
• Balance of cultural and scientific protocols

Findings
• Statistical sig. decrease in systolic blood pressure for both groups
• Hula: appropriate and appealing
• Impacted cognitive, emotional spiritual and physical aspects of health
• Created strong social support and negative emotion management
Translating Culture Based Programming to Dementia Practice

• Building on successes of CB programming with other health issues:
  
  • Listen to the implicit specific cultural practices grounded in individual and group's particular **preferred care and communication**
  
  • Pay attention to the Importance of **family engagement** but also “every day” **realities and complexities** of culture AND dementia care
  
  • Commit to **respectful and knowledgeable care** by providers; e.g., culture Iceberg, health equity framework [resiliencies and adversities], and person-centered care
Case Example: Native Hawaiians Health and Social Disparities

- Pride in history and culture
- 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 on racial/ethnic and cultural populations
- BUT: CT/CB programs with other health concerns have produced positive health results; i.e., increased access, improved health
- Test CT/CB approaches in dementia care & target specific health factors & behaviors to reduce incidence (?), provide respectful care
A recent study of kūpuna and `ohana caregivers on aging and care preferences found:

(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 who were knowledgeable of their community
Like a brave hero traveling into the unknown—without a compass… my grandma travels into the unknown every day.

Dementia, Caregiving, & Native Hawaiian Families

*Developing a Youth Dementia Storybook*

Ha Kupuna National Resource Center for Native Hawaiian Elders
Why Youth Caregivers?

- 1.3 million caregiving children in the US
- 38% provide care for grandparent
- 34% provide care for parent


250,000 children and young adults between the ages of 8 and 18 are child caregivers to those with Alzheimer’s disease or dementia.

Many remain invisible from health/social services systems…
What is Alzheimer’s Disease & Dementia?

Will my parents get dementia? Will I?

Why doesn’t Grandma recognize me?

Why is Grandpa calling me bad names?

It’s hard to talk about but I really need to talk.

How can I help?
Pomai and Papa

- Storybook about dementia
- Aimed at youth aged 8 – 12
- Kānaka maoli more likely to live in intergenerational households
- 12% of Hawaiian kūpuna live with moʻopuna and 7% of elders of other ethnicities in Hawai`i reside in intergenerational homes
- Compared to 3.7% national average
**Curriculum Development**

**HALI ‘A** – In Hawaiian, hali’a means memory— the things we remember from childhood and the things we remember we must do for tomorrow.

**HALI ‘A** also is a way to think about memory loss caused by changes in the brain called **Alzheimer’s Disease (AD)**. When a person gets AD, many memories may be “erased”

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**H: **Hard to remember names, events, basic information. May lose track of days, dates, time of year. Hard time finding things.

**A: **`Ano (a person’s basic nature, personality) changes---with these changes come confusion, frustration, anger, impatience, and other feelings.

**L: **Loses judgment, has harder time problem-solving.

**I: **Increasing difficulty to remember words. Writing and speaking affected.

**A: **At- risk of wandering and other un-safe behavior.
To summarize—practice considerations:

- Some needs are universal; others are not

- Assessing a person/family’s cultural values, historical background, and impact of prejudice/discrimination on their preferred use and satisfaction with care can help tailor interventions for optimal assistance

- Important to assess your own knowledge of a group’s culture and history to understand impact on needs, service design, and delivery

- Importance of staff training and education on history and culture and respectful and compassionate care

- Work closely with researchers and those in the community for design, testing, and dissemination of dementia care efforts that incorporate culture
Increasing racially/ethnically diverse State kōpuna 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, care preferences not understood or met, actual/perceived discrimination in accessing services, ways of coping, varied family structure)

Great need for accessible/affordable LTSS for elders and family especially with the dementias

Extend the testing of culturally-based LTSS to dementia care.

Support for providers in continuing education on practice implications around the complexities of dementia and culture
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!