Culture and Caregiving

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First, a better understanding of “culture” is needed

- ”Culture” does not mean “minority.” Please stop that.
- Wrong: culture = minority= problematic= now we have to deal with those different people apparently afflicted by ethnic culture.
- Culture is not a list of traits that “they” do. Culture is an ever changing process of adapting to life situations using precepts, beliefs, and values.
- For interventions intended to reach culturally different population segments, do we really mean culture? Or, do we mean an individual, a family, or a community, or a society? Or, multi-level?

Culture and Caregiving

- For all people, caregiving is embedded in cultural systems.
- Broad cultural values of the mainstream America:
  - Hyper-individualism
  - Hyper-independence
  - Hyper- self-destiny
  - Hyper-fear of mental aberrations
- These cultural values are exactly those reduced by dementia.

Why are there support groups and conferences on helping caregivers?

- Well, obviously, dementia care is hard work.
- The deeper question is *WHY* is it such hard work?
- One cultural answer: post-marital neolocal residence patterns in U.S.
  - In many societies, every marriage builds additional members of the household. (matrilocal/patrilocal)
  - Here, every marriage *reduces* the number of people in the household.
- If dementia symptoms occur, many older families are two members (one of whom is affected), or extended members are dispersed and collectively place responsibilities on one or few members.
- Isolated caregivers band together forming fictive kin groups (artificial families) that we call support groups.

Cultural Constructs of Dementia & Caregiving

- Biomedically based explanations
- Lay understandings
- Mixed use of lay and biomedical
- Culturally informed notions of dementia:
  - Hallucinations: may be perceived as positive (Henderson/Henderson 2002)
  - Dementia “worsening” may be perceived as expansion into another reality (Jacklin, et al., 2015)
  - Dementia due to personal failings (Traphagan, 2000)

- *How do these culturally based constructs effect caregiving??*

Intra-familial cultural dynamics:

- Elder status in household >> loss of capacity >> what happens?
- Cross-generational caregiving >> grandchildren caregivers >> ACE?
- Sex role variance >> male = manager; female = hands-on
- Gender role expectation >> heavily female even to female in-laws
- Stigma >> changed social status >> reduced reciprocal obligations
- Acculturation variance by age >> younger women disavow female-exclusive caregiving in favor of shared female/male caregiving; contrary to parental generation

Research Concerns Re: Ethno-cultural/Indigenous Caregiving

- For some ethno-cultural/Indigenous populations, small population numbers in their communities may exclude them from being collaborators in studies that demand large sample size.
- RCT methods may be unfeasible/unwelcome in some ethno-cultural/Indigenous communities.
- Focus on medicalized concepts of dementia may not map onto the perspectives of ethno-cultural/Indigenous populations.
- Need for expertise in cultural systems and cultural negotiations for mutually agreeable collaboration, research design, research implementation, and data analysis.

How to address culture and caregiving??

- Culture-fair; Culture-free
- Or, culturally adaptable caregiver intervention
- To develop a multi cultural adaptable intervention, there is a need for expertise from the social and behavioral sciences to work together with other disciplines to develop a multi-level, multi-component intervention.
- Example: *SAVVY Caregiver for Indian Country* (Henderson, 2005)
  - Requires some modest education in identification of cultural and social factors in one's local life space.
  - Requires some guidance by providing examples of local preferences can be incorporated into caregiver applications

Orthogonal Perspective: Caregiving is never just one thing, so there's not just one fix Henderson 2015

- Multi-level interventions: Individual (Ex: personality/knowledge), Family (Ex: age/gender mix; household density), Community (Ex: small/racist/resource availability), Societal-Political (Ex: national health care/medical priorities), Cultural concepts (Japan: moral values; Oklahoma Choctaw: positive interpretation of hallucinations)
- Multi-stimulus interventions: Dementia education + physical activity + cultural fit >> culturally valued exercise may not be in a nice gym with electrified equipment.
- Intersectionality of multi-stimulus interventions: Orthogonal chronic disease model = cultural perspectives influencing caregiver contemplations that operate in the context of an ever-changing, dynamic set of symptoms

Putting culture into intervention research on caregiving

- Involve members of the ethno-cultural/Indigenous group in intervention development as advisors and co-developers
- Become aware of intra-group variation in beliefs, values, and behaviors (generation, SES, acculturation variance, gender, fluid gender identity, religion, etc.)
- Give value to the ethno-cultural/Indigenous group's internal knowledge and response systems (ethno-cultural/Indigenous epistemologies can explain cultural systems)
- Showing value to more than Western medicines' knowledge-claims gives credibility and sincerity to the collaboration.