

# THE DYNAMIC WEB OF DEMENTIA CAREGIVING: BEYOND THE TASKS

1. The experience of caregiving is not the set of tasks.
2. Caregiving is not a solo experience even when it might look like it.
3. There is no caregiver in the singular. There is a caregiver network that may be contained inside the mind of the caregiver in terms of knowledge, emotional capacity, and other resources internal to them. Plus, networks include those outside the caregiver, too.
  1. Example: Man whose wife had Alzheimer's illness. They both lived in the same house. He held in his mind an imaginary wife that was his wife during her pre-dementia life. His wife living with dementia was lovingly cared for but as if she was a guest in the house with him and his imaginary vision of his pre-dementia wife.

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1. Caregiving is done in a larger context beyond the caregiver and receiver.
2. Caregiving context involves the place, household members, non-household family, friends, clinical and clinic staff, CHR's, tribal health programs, tribal elder programs, etc.
3. Context also refers to the caregiver's personal emotional resources, personality, beliefs about dementia causation, fantasies about a wrong diagnosis, anxieties about the future, end of life decisions, and more.
4. When we take a reductionist view of caregiving as tasks and tricks, we miss the manifold experience of caregiving—you know, where caregivers really live.

# **THE DYNAMIC WEB OF DEMENTIA CAREGIVING: *BEYOND THE TASKS***

**#1. How might the high value and social prestige of Indigenous elders cause caregivers to develop excessive guilt about their sense of fatigue, possible resentment, anxiety, caregiver failures, and depression?**

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**#2. In response to the high value accorded Indigenous elders, does the highly dedicated, intensive Warrior Caregiver develop ADRD by proxy?**

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**#3. Is the caregiver responding to a person experiencing “cognitive impairment” (a static implication) or “declining cognition” (an ever-changing condition)?**

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**#4. When does the general status and role of a loving spouse, adult child, grandparent, or friend change to the master status and role of “Caregiver” to an Indigenous elder?**

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## #5. What if we thought of Alzheimer's illness care as : **Ceremonies of Elder Honor**

1. NOT a series of just tasks
2. NOT just body care
3. NOT just bed care
4. But adopt the actions of caring as having a higher meaning and value, possibly inducing a greater sense of household harmony.
5. Yes, still accompanied by expressions of distress, but met in more meaningful, resilient ways

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**#6. Does code switching from an unstated view of “Dying with Dementia” to “Living with Dementia” help reduce negative attitudes? Stigma? Tasks? Affection? If so, how much? Where is the data?**



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**#7. Don't just do something, stand there!**

**Benefits of objectifying the person with dementia.  
(Adapted from *The Savvy Caregiver for Indian  
Country*)**

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## #8. What does Contented Involvement (per *Savvy Caregiver for Indian Country*) look like in AI/AN tribes and villages?

1. Canoe journey: preparation, rituals, prayers, being at the water to see/feel the event, etc.
2. Powwow/social dance: drum groups, regalia, feeling the energy, etc.
3. Culturally favored foods from the Earth
4. Culturally favored music and instruments: drum, flute, eagle bone whistles, etc.
5. Culturally favored objects: medicine bags, medicine bundles, pottery, feathers, sage/cedar, etc.
6. Lots of YouTube videos on AI/AN activities