# Doing Dementia Better: Anthropological Insights

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- Anthropology of dementia • Agism • Personhood
- Embodiment

## THE CULTURAL MEANING OF PERSONHOOD AND DEMENTIA: I AM NOT DEAD YET

> *I'm not sure the doctor knew how to deal with Alzheimer's. It was just diagnosed and that's it. "It looks like she may have Alzheimer's and we'll just have to wait and see." …I felt like the doctors were really not much help to me. They didn't know what to do… It seems that once a person has been diagnosed with dementia, many doctors just ignore them. …I would ask the doctors how he was doing and they would say fine, but when I went to see him I found him sitting with his head in his lap.*[1]
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> *"I was terrified the entire time [I took care of my mother. And after I dropped her off at a nursing facility], when I got home, I took the nightgown she had worn, the one I lent her, and put it in the trash. Just in case Alzheimer's was contagious."*[2]

This article reveals the deleterious impact that cultural assumptions about dementia have on the care provided, and, through an exploration of anthropological theories of personhood, suggests a model of Personhood-Centered Care, comprised of strategies for preserving personhood in the face of dementia, to improve quality of life. As health care professionals, we live and work within a broader cultural context, and while medical training and practice engage us in a specific subcultural view of aging and dementia, we are also of a piece with the broader cultural fabric. Attitudes and preconceptions about aging, personhood, and the valued goals of life shape us and our disposition in clinical practice.

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Patients with dementia and their families frequently report that they are less than pleased with their clinical encounters.[3,4] Trainees regularly suggest to me that they do not think they are well prepared to care for patients with dementia, and the literature supports their impression[5–7]; by second-year residency, they have well-developed clinical responses to shortness of breath and chest pain but are often unsure what to do when facing a confused older patient. Within the context of aging demography, evidence suggests that medical education may actually decrease one's interest in working with elders,[8] and agism within medical practice is increasingly noted.[9–11] Adelson has coined the term dementia-ism to refer to the distaste regarding working with patients who have dementia.[12] Indeed, many of us as doctors and nurses share the widespread cultural horror and fear about dementia.[13,14]

Dementia, or neurodegenerative disease, is a disease category, and yet it is widely described in popular and professional media as a horror story. Alzheimer disease "eradicates the essence of the person"[15] and causes the "unbecoming" of the self[16]; "the victim of Alzheimer's is one whose mind has been dissolved, leaving only a body from which the person has been removed"[17]; and "the victim of Alzheimer's must eventually come to terms with…the complete loss of self."[18] Are we describing a disease, or the plotline of a horror movie? One family caregiver captures the essence of our social imaginary by describing that Alzheimer disease is a brain-eating monster: "We started to get a good idea of the size and shape of the beast called Alzheimer's… To it, brain tissue is brain tissue, all of it equally tasty."[19]

Once in my geriatric consultation clinic, a patient's adult son said, "When we first got the verdict…wait–I don't mean Verdict–what's the word, I cannot think of it?" "Diagnosis?" I asked. "Yes: Diagnosis, well it felt more like a verdict." I hear similar comments when several times each year I lead interactive workshops on dementia; participants, including medical trainees, allied health professions, or individuals in the lay community, reenact the stereotypes and assumptions of cultural approach to aging and dementia. And not infrequently, the belief that people with dementia are not really alive penetrates the clinical setting:

> *Glenn was a patient with dementia, who lived in a nursing home. He conversed in simple sentences, flirted and laughed frequently with female staff, participated with apparent enjoyment in all musical recreational activities, and ate with gusto. His daughter Glenda requested a hospice referral, and as the attending physician, I requested a Family Meeting to better understand her thoughts and feelings. When invited to open the meeting, Glenda, who was seated next to her father, did not hesitate to tell us why she requested hospice: "My father is dead!" "This man is not my father!" Hospice, she felt, would be a method to help the physical body die and to match more accurately with what she perceived as her already-dead father. Although the social worker, nurse, and physician shared information about how Glenn was enjoying activities, relationships, and food, the daughter was not buying it. "My father is dead! This man is not my father!" Each time she said this with strong negative affect, her father seated next to her shrunk further into his wheelchair, a stricken look on his face intensifying.*

This case vividly depicts how the cultural perception of people with dementia as the walking undead increases suffering. But why do we perceive people with dementia as the already-dead and the not-truly-human? And what can we do to change course?

The first step to treating patients with dementia differently is to begin to recognize how cultural notions of personhood, of what makes a person a person, shape the meaning and experience of dementia. This article explores diverse models of personhood (**Table 1**) and their impact on the meaning and experience of dementia. Anthropological insights can help us as physicians and nurses to better understand