



Sociocultural Aspects and Determinants of Dementia Care for Minority Ethnic Populations

Ana R. Quiñones, PhD
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*Second Workshop of the Committee on Developing a
Behavioral and Social Science Research Agenda on
Alzheimer's Disease and Alzheimer's Disease Related Dementias*

Charge of the commissioned paper

Address health disparities among populations living with Alzheimer's disease and Alzheimer's disease related dementias by review existing research on:

- **Differences** regarding AD/ADRD recognition, diagnosis, and care practices
- **Stigma** associated with the disease and providing care in different populations
- **Attitudes or cultural differences** with respect to education, guidance, and support for AD/ADRD care
- Promising areas for **future research**



Co-authorship Team

- Anda Botoseneanu, PhD, University of Michigan-Dearborn
- Heather G. Allore, PhD, Yale University
- Stephen Thielke, MD, University of Washington
- Jeffrey Kaye, MD, Oregon Health & Science University

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General outline

- I. Epidemiology of AD/ABRD in minority ethnic populations
- II. Addressing whole-person patient-centered dementia care
- III. Sociocultural aspects in decisions to seek care/health seeking behavior of older minority ethnic populations and their caregivers
- IV. Promising areas for future research

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I. Epidemiology of AD/ADRD in minority ethnic populations

- National U.S. data trends
 - Differences in AD/ADRD prevalence, earlier onset
 - Greater severity at initial assessment/diagnosis, and greater cognitive decline at subsequent follow-up
(Langa et al., 2017; Mayeda et al., 2016; Mehta et al., 2008; Dilworth-Anderson, et al., 2008; Cooper et al., 2010)
- Early access to assessments and diagnosis is critical
 - Population-based approach to improving dementia care
Connection to social services and supports
 - Early initiation to advance care planning, palliative care, financial planning
(Reuben et al., 2019; Clark et al., 2005; Ayalon & Arean, 2004; Hinton et al., 2004)



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II. Addressing patient-centered dementia care

- Taking full stock of all chronic conditions and care needs
(Fabbri et al., 2015; Quiñones et al., 2018; Doyle and Rubinstein, 2013)
- Consideration of treatment burden or the workload people with dementia and their caregivers are doing
(Spencer-Bonilla et al., 2017)
 - Treatment burden and caregiver strain are inextricably linked
 - Work and workload may be more acutely felt in minority ethnic populations (who on average, have greater burden of chronic conditions)



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III. Sociocultural aspects in decisions to seek care

- Conceptual mechanisms
 - Cumulative Complexity Model (*Leppin, 2015; Spencer-Bonilla et al., 2017*)
 - Cumulative Inequality Theory (*Ferraro & Shippee, 2009*)
 - Sociocultural Health Belief Model (*Sayegh & Knight, 2013*)
- Cultural norms, values, beliefs, and roles shape definitions, and differences in response to symptoms (*Dilworth-Anderson & Gibson, 2002*)
- Drivers of health care seeking behavior and barriers to assessment and diagnosis (*Gelman, 2010; Connell et al., 2007; Ayalon & Arian, 2004; Hinton et al., 2004; Calia et al., 2019*)
 - Unfamiliarity with symptoms and lack of knowledge
 - Normalization of early symptoms as “normal aging”



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III. Sociocultural aspects in decisions to seek care

- Drivers of health care seeking behavior and barriers to assessment and diagnosis (*continued*)
 - Stigma and fear associated with a diagnosis
 - Distrust of clinical and research teams
 - Considerations framed as the five A's of access:
 - Affordability – *somewhat mitigated in this age group*
 - Accessibility – *are there services nearby?*
 - Availability – *are specialized services offered nearby?*
 - Accommodation – *are services open when convenient?*
 - Acceptability – *is there diversity in the workforce?*



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IV. Future directions

- Construct validity in AD/ADRD testing
(Dilworth-Anderson et al., 2008)
 - Validation of dementia assessment tools in minority ethnic populations
 - Attentiveness to language, acculturation, cultural orientation, education and literacy influences in current assessment tools
- Greater granularity and attentiveness
(Hinton et al., 2004; Hargrave et al., 2000; Dilworth-Anderson et al., 2008)
 - Studies that involve a greater number of minority groups (AI/AN, Asian)
 - Subgroup differences: heterogeneity within many categories such as Latino and Asian; immigration, and linguistic dialect



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IV. Future directions

- Identify best practices and methods for outreach and communication
(Connell et al., 2007; Dilworth-Anderson & Gibson, 2002)
 - Identify best mechanisms for transmission of information
 - Use cultural and social information in the design of programs
- Diversification of the workforce
 - Training, staffing, recruiting, retaining



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Q & A

Questions or comments?

Ana R. Quiñones, PhD
Department of Family Medicine
quinones@ohsu.edu

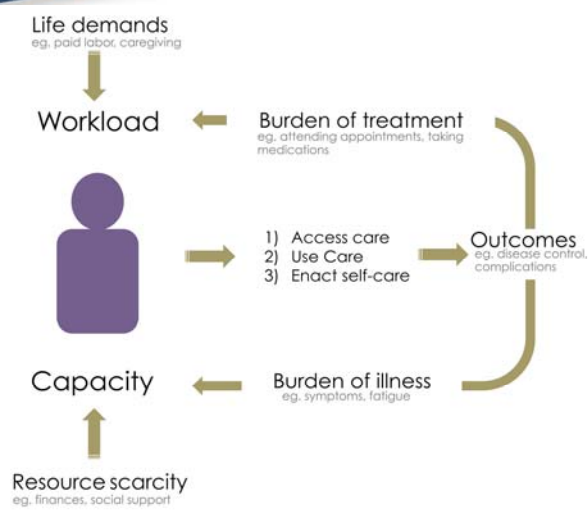
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EXTRA

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Cumulative Complexity Model



*Note: from
Spencer-
Bonilla et al.,
2017*

Cumulative Inequality Theory

Table 1.
Axioms and Propositions of Cumulative Inequality Theory

Axioms	Propositions
1. Social systems generate inequality, which is manifested over the life course through demographic and developmental processes.	<ul style="list-style-type: none"> a) Childhood conditions are important to adulthood, especially when differences in experience or status emerge early. b) Reproduction is a fulcrum for defining life course trajectories and population aging. c) Influenced by genes and environment, family lineage is critical to status differentiation early in the life course. d) Cohorts provide the context for development, structuring risks, and opportunities. e) Consider inter- and intra-individual processes and use analytical techniques that explain variability on multiple levels or in multiple domains.
2. Disadvantage increases exposure to risk, but advantage increases exposure to opportunity.	<ul style="list-style-type: none"> a) Consequences of advantage may not be the inverse of disadvantage. b) Inequality may diffuse across life domains (e.g., health and wealth). c) Trajectories are affected by the onset, duration, and magnitude of exposures.
3. Life-course trajectories are shaped by the accumulation of risk, available resources, and human agency	<ul style="list-style-type: none"> a) Human agency and resource mobilization may modify trajectories. b) Turning points in the life course may alter the anticipated consequences of a chain of risk. c) The dialectic of human agency and social structure is essential to cumulative inequality. d) Unfavorable trajectories can be mitigated by the magnitude, onset, and duration of resources; resources can also accelerate favorable trajectories.
4. The perception of life trajectories influences subsequent trajectories.	<ul style="list-style-type: none"> a) Social comparisons shape trajectories. b) Favorable life review linked to self-efficacy. c) Perceived life course timing influences psychosomatic processes.
5. Cumulative inequality may lead to premature mortality; therefore, nonrandom selection may give the appearance of decreasing inequality in later life.	<ul style="list-style-type: none"> a) Cumulative inequality creates compositional change in a population. b) Population truncation may give the appearance of decreasing inequality. c) Test for selection effects. d) Interpret results in light of event censoring and cohort inclusiveness.

Note: adapted from Ferraro, Shippee, & Schafer (2009)



Sociocultural Health Belief Model

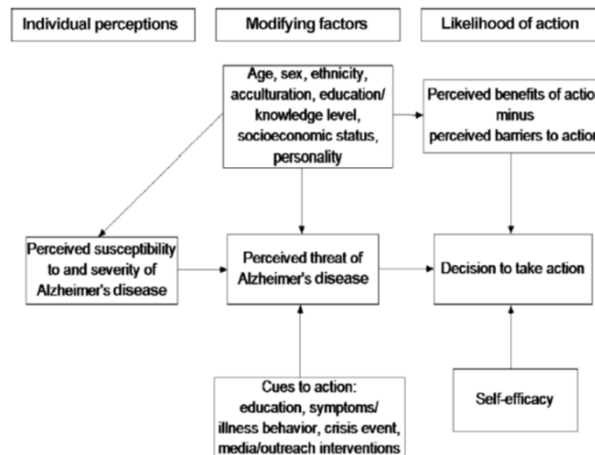


Figure 1. The Adapted Health Belief Model for health behavior actions.
Sources: Hughes *et al.*, 2009 and Janz *et al.*, 2002.

Note: from Sayegh & Knight, 2013

