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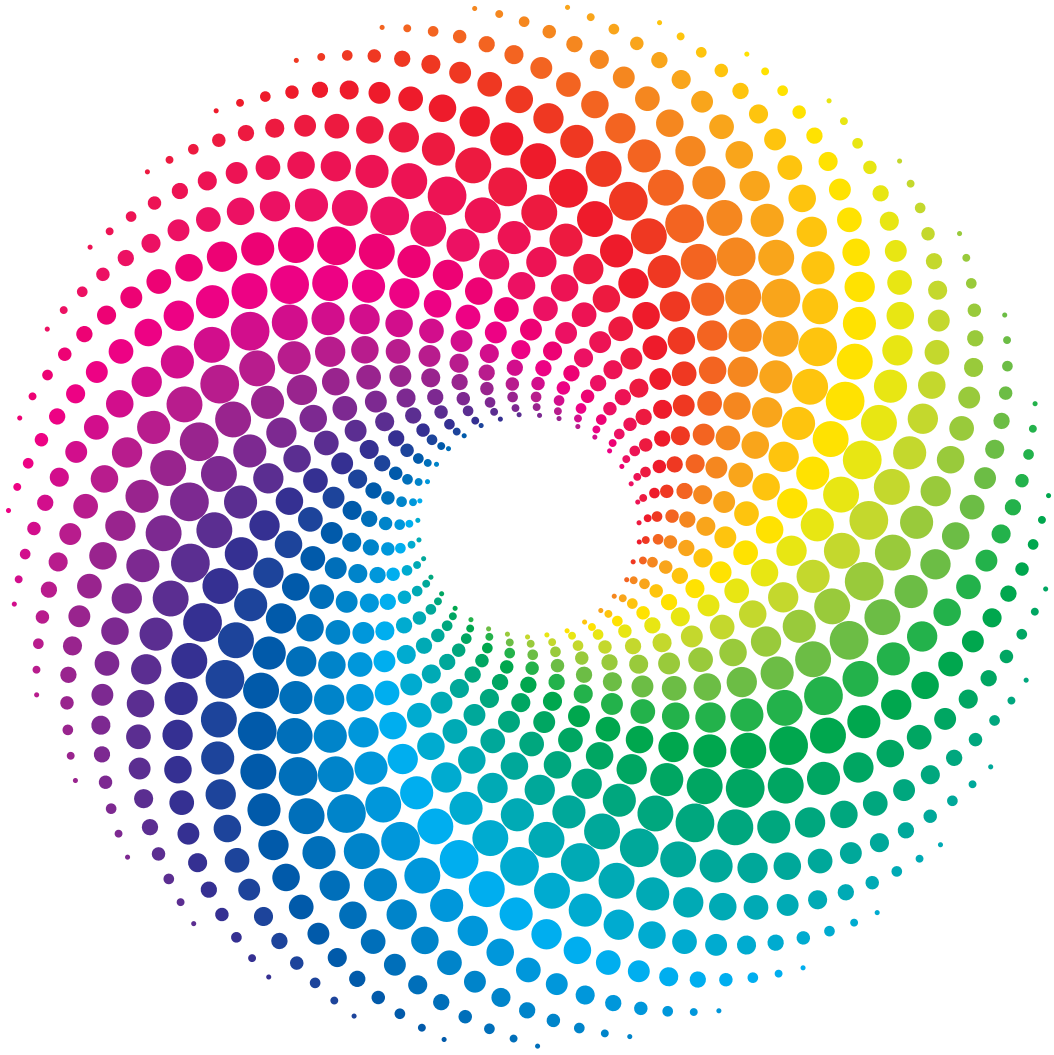

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# Cultural Construction of Dementia Progression, Behavioral Aberrations, and Situational Ethnicity: An Orthogonal Approach

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Neurodegenerative diseases, such as Alzheimer's disease and related dementias, induce caregivers already struggling to cope with the behavioral aberrations of dementia to constantly update their cultural construction of the disease because the outward symptoms used to interpret it are in constant flux. For ethnic minority caregivers, particularly, coping is a process of tracking a moving set of symptoms, making cultural sense of them across time, and negotiating a medical environment that can be hostile to them because of their "nonstandard" cultural health beliefs. In the midst of a constantly changing disease, achieving optimal communications with the medical establishment causes the ethnic minority caregivers to change their behaviors to better fit the expectations of the clinic, then retreat to their own cultural comfort zone only to continue oscillating between cultures for the duration of their caregiving responsibilities. Ethnic minority dementia caregiving is conceptualized here from an orthogonal perspective in which the moving elements of the ethnic minority dementia experience intersect in numerous ways and produce many coping strategy permutations corresponding to the evolving disease and its cultural constructs.

**Keywords:** dementia; culture; ethnicity; disease model; chronic disease progression

The purpose of this article is threefold: (a) expand the cultural construction of disease model to incorporate more flexibly the progressively changing symptom patterns common to many types of chronic disease, (b) use the progression of dementia symptoms as a chronic disease model, and (c) further the use of the model by examining dementia coping among ethnic minority caregivers by using a multistage vignette. Ethnic minority life, caregiving routines for persons with dementia (PWD), and the continuously changing disease state of dementia all move in a clockwork fashion. The cultural construction of disease is constantly revised by the caregiver because the cognitive and behavioral changes of dementia affect the PWD. Ethnic minority life is often characterized by routinely and purposively shifting behavioral norms to best fit the multitudes of social situations encountered outside their home and family cultural environment.

Exploring these multiple commingled factors requires another conceptual framework designed to allow disease models to adjust to changing symptom patterns over the course of the chronic disease experience while simultaneously accounting for the multicultural life experience of ethnic minority caregivers. The orthogonal model for the multifactorial analysis of ethnic minority cultural identity and cultural identification serves well to emphasize the shifting factors of ethnic minority cultural identification itself (Oetting & Beauvais, 1991; Oetting, Swaim, & Chiarella, 1998) and can be nested into another framework likewise in constant flux, that of the progressively worsening symptoms of dementia.

## CULTURAL CONSTRUCTION OF DISEASE MODELS

Medical sociology and medical anthropology for many years have constructed the nature of sickness as having at least two different domains for analysis: (a) disease and (b) illness. The disease domain focuses on the pathophysiology of sickness. Pathophysiology refers

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to the biological phenomena that lead to deleterious physical outcomes. The illness domain of sickness refers to the human experience of discomfort and other symptomatic awareness that a person has by which they judge themselves to be sick.

Illness dynamics have been examined in a multitude of ways (Conrad & Barker, 2010). For example, Parsons (1951) developed his notion of the "sick role" in which a person entered a deviant social state that led to some relief of social expectations, such as job or kinship obligations. Sick people were expected to behave in ways that would return them to a normal role and social condition. Later, Mechanic (1968) developed his schema for "help-seeking behavior" in which he focused on the illness incident as a series of experiences, evaluations, and action steps leading to the resolution of symptoms. Also, Friedson (1970) developed the notion of the "patient career" in which the transition from ordinary social status to "patient" status caused a new set of roles, role performances, and expectations to emerge about how one should behave with the new label of *patient*. More recently, Pfifferling (1981) and Kleinman (1980) developed schemas to elicit a sick person's beliefs about the nature of their disease. This process assisted in bringing together the disease and illness domains. Although people described their health beliefs relating to their disease, they also, through specific questions asked of them, revealed their notions regarding the social, psychological, and cultural aspects in which their disease is intertwined.

Medical anthropology has for decades honed the concept of the cultural construction of disease. From a social to a cultural viewpoint, the cultural construction of disease concept refers to the ways in which people interpret and symbolize sickness. Cultural patterns seemingly unrelated to disease and illness can influence how sicknesses are managed. For example, consider a surprising interaction between American cultural kinship systems and Alzheimer's disease. American families are organized along a nuclear family focus which concentrates human resources and financial resources across only a small number of people. Typically, families will grow and age through childhood, adolescence, and adulthood. As the children become adults, marriages occur, which, rather than bringing more people into the household, cause people to leave their natal home. American newlyweds may be seen as almost frantically trying to live wherever their parents don't. Regarding continued aging and the possibility of the need for caregiving to an older parent, the resource bank of hands-on caregivers is diminished. This is because of the postmarital, neolocal American kinship residence pattern that serves to concentrate caregiving tasks and burdens on one or a few people, whereas postmarital residence patterns in other cultures can bring caregivers to the household (Henderson, 1987, p. 367).

However, another facet of the cultural construction of disease model incorporates environmental, physical, and sociocultural elements of human existence into a single, multifaceted web of interconnected phenomena, which result in sickness. This biocultural or syndemic (Singer, 2009) approach allows for the possibility of culture causing or strongly contributing to a sickness. For example, diabetes among American Indian populations is rampant. Although there may be some genetic pressure toward diabetes in this population, the biocultural or syndemic approach would emphasize the multiple psychosocial and politicoeconomic stresses persistent over the lifespan that result in chronic conditions such as diabetes (Wiedman, 2014). Dementia is also subject to such nonbiological forces that collectively work to increase risk potentials (Henderson, Carson, & King, in press; Lock, 2013; Whitehouse, Gaines, Lindstrom, & Graham, 2005).

Regardless of which model is used, discomforts and diseases of all kinds occur in a cultural web of beliefs, values, and perceptions, which influence the behavior of those experiencing noxious bodily changes. It is from this constantly changing web of life that the interpretations of bodily and behavioral perturbations are derived.

For most chronic diseases that do not produce obvious bleeding or other acute loss of visible vital fluids (e.g., hypertension, rheumatoid arthritis, or Alzheimer's disease and related dementias [ADRD]), the interpretive "data" used by family and friends to gauge what is "normal" or "abnormal" is observable behavior. ADRD, for example, causes behavioral aberrations that are disruptive and disturbing to the PWD in the early stages and to others throughout its course. It is this latter phenomenon that has proved so disturbing throughout all societies over time. Historical records show the strong likelihood of interpreting unusual behavior as supernaturally induced by maleficent forces. Even today, the stigma of seeking mental health services and the low reimbursement rates to clinicians may be a distant echo from past fears of unusual behaviors with no externally observable causes.

Behavioral aberrations specifically refer to disturbed behavior because of brain dysfunction. Irrational thoughts are enacted in ways that produce observable, unusual, and sometimes dangerous behaviors. Focusing on behavioral aberrations allows for greater distance from the medical descriptors of the symptoms to which those caregivers must respond. Continuing to describe ADRD in terms such as *amnestic syndrome*, *agnosia*, and *neuronal depopulation* neglects the caregivers' lived-experience of ADRD and constitutes a received, overriding medicalized perspective that obscures the personhood of the PWD (Castillo, 2011).

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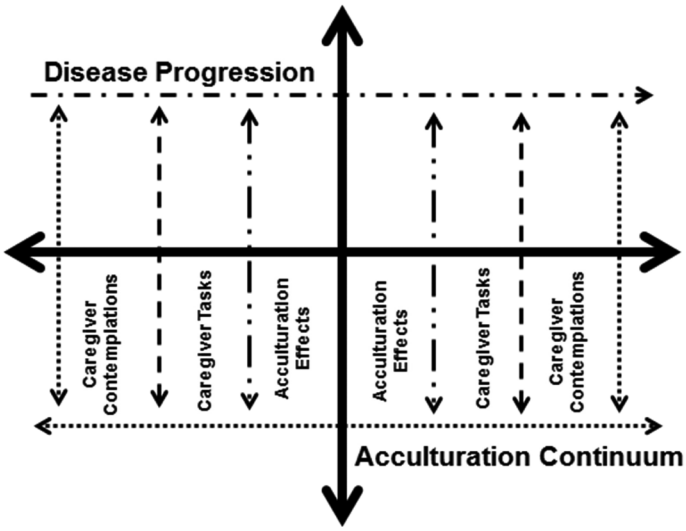


**Figure 1.** Disease progression, caregiver tasks, and acculturation effects.

## ORTHOGONAL CHRONIC DISEASE MODEL

The use of an orthogonal chronic disease model (OCDM) would result in a more realistic window into the lived experience of chronic disease by the ethnic minority PWD and/or those caregivers around them. Orthogonal models account for the effects of multiple intersecting variables. In this case, the OCDM affords a dynamic multifactorial approach with temporal and cultural changes intertwined with symptom progression. The interconnection of disease symptoms, caregiving tasks, and ethnic minority identifications are important to recognize because these are continually changing over time. The OCDM schematic includes the intersections of disease progression, caregiver tasks, and acculturation effects (Figure 1).

### Disease Progression

Many chronic diseases worsen over time rather than remaining stable. For example, rheumatoid arthritis and Alzheimer's disease present slowly but become life-altering conditions as time goes on. Changes can be so radical as to make the early stages appear completely different from the late stages, although symptoms are perceived as stemming from one disease. From the caregiver's perspective, a single disease would be experienced over time as a series of categorically different disease states that cause caregivers to continually revise their explanatory models, tasks, and future expectations of symptom change.

They would draw from their ethnic minority wellsprings to bring explanation, understanding, and the self-comfort of coalescing a complex set of experiences into cultural categories meaningful within their ethnic minority milieu.

### Caregiver Contemplations

As symptoms change, so do caregiving tasks. Caregiving tasks are like "bed and body" care in long-term care nursing. However, for conditions in which cognitive abilities are slowly declining, such as the dementias, caregivers become critical and mutual conegotiators and cointerpreters of all aspects of life with the PWD. These caregivers not only perform tasks but they also engage in a kind of contemplation regarding their predicament. Their loved one looks the same but is slowly changing and leaving their relationship increasingly one-sided. Rationalizing this predicament is a constant and frustrating philosophical exercise.

### Situational Acculturation

For ethnic minority caregivers, it is important to remember that acculturation status is not static but slides on a continuum. The movement along the continuum is a function of needing to conduct daily life effectively but in various culturally situated circumstances inside and outside the dominant society. One's "presentation of self" (Goffman, 1959) will be adjusted to fit best into the social and cultural demands of each particular situation. Clinical encounters with biomedicine often provoke "cosmopolitan" behavioral enactments in ways considered appropriate to the medical setting. However, disease causation models common and valued in the ethnic minority setting may not be valued in the biomedical setting. Naturally, the patient/caregiver wishes to avoid the social punishment of essential dismissal by biomedical practitioners so that whatever medical benefit is present can be discerned and added to their home care strategies.

## ETHNIC MINORITY LIFE AND ORTHOGONAL MODELS

The usage of the orthogonal concept is extrapolated from ethnic minority studies attempting to reflect the dynamic process of populations living multicultural lives. Orthogonal models in ethnic studies came to replace more unidimensional models for understanding the dynamics of ethnic minority participation in new cultural settings. Early accounts of such processes held the position that as one culture was newly learned, the personal home culture was lost. Later, multicultural models promoted the notion that ethnic minorities could have high levels of identification with their new cultural setting as well as the original home culture, but this model neglected those who, even over time, remained at a low level of cultural identification. The orthogonal model asserted that cultural identification with one culture can occur in a way that produces a condition in which an ethnic minority person identifies strongly with their home culture and, simultaneously, with the new culture, but retains their own *personal* cultural identity. For this to occur, the dynamic intercultural life experience of ethnic minorities had to be accounted for by awareness that ethnic minority

*Caregiving tasks are like "bed and body" care in long-term care nursing.*

people may possess multiple cultural models in a simultaneous, overlapping, interdigitated way (Oetting et al., 1998).

Orthogonal models account for multiple moving and intersecting elements of culturally relevant factors that combine to produce cultural domains. Cultural domains can be various things, including disease categories, functional status stages, and, here, the cultural construction of disease as a product of combined multiple factors that constantly change in correspondence with the changing symptoms of chronic progressively degenerating dementia.

## DEMENTIA

Neurodegenerative diseases, such as ADRD of late life, constitute a rapidly growing global problem (National Institute on Aging, 2014). Increased human longevity is the main reason. Lifetime threat for ADRD is greatest with old age so that more and more people live into the ages of greatest risk resulting in more people and their caregivers suffering from the mental and emotional declines symptomatic of these conditions. That society and medical intervention/prevention lags behind in effective amelioration of ADRD is partly because of the fact that never before in the history of humankind have so many people lived for so long (Coreil, Bryant, & Henderson, 2001) and, consequently, it constitutes an unprecedented demographic event (Henderson & Henderson, 2010).

Ethnic minority populations are likewise living into the ages of greatest risk for ADRD. For example, the American Indian and Alaska Native population aged older than 65 years is expected to grow from 212,605 in 2007 to a projected 918,000 by 2050 (U.S. Department of Health and Human Services, 2014). Outside of the United States, it is projected that four-fifths of the people older than 60 years will be living in developing countries (United Nations, 2013). Worldwide, the fastest growing age cohort is the older-than-85-year group (National Institute on Aging, 2014), with the life expectancy of this group steadily increasing (United Nations, 2013). Unfortunately, that is exactly the age threshold at which the ADRD diagnosis applies to almost half of the population.

The term *ethnic minority* will be used here in reference to subgroups within larger populations that have significantly different cultural value systems, language, and an ethos separate from the majority group. In real practice, ethnic minority status is highly variable as an intercultural difference, but ethnic minority factors are also present in a great range of intragroup variations as well. Moreover, the behavioral expressions or enactments of ethnic minority norms will vary from one situation to another to create a mosaic of intercultural, intracultural, and situationally distinctive behavioral features of ethnic minority life. The ethnic minority life mosaic is what is explored here, but in the context of chronic, progressively worsening cognitive and behavioral deficits that, in turn, require help from others to negotiate even the simplest aspects of daily life.

The common cultural construction of disease model is too static to properly account for progressively worsening chronic disease. Moreover, it ignores the downstream effects of the disease on other nonafflicted family members who, to some degree, experience the chronic disease by proxy because of envelopment in the disease resulting from 24/7 caregiving. Ethnic minority families will usually seek biomedical help but experience it in the context of their own health beliefs and practices. One problem lies with biomedical hegemony and its bias against personal and ethnic minority health beliefs and practices. This leads to ethnic minority families altering their presentation of self when in the biomedical practice setting to receive more information and maintain a stronger sense of respect by not being dismissed as ignorant. Such families are coping with both their loved one's chronic, incurable disease and biomedical bias, intentional or not, against unorthodox cultural health beliefs and practices.

I intend to make the cultural construction of disease model more elastic and improve its analytic power with specificity to chronic, progressively degenerative disease. First, I will present the notion that progressively worsening chronic disease is experienced by PWDs and those around them as *a disease with one name but with an ever-changing set of radically different disease states and experiences over long periods of time*. Consequently, PWD and their caregivers, implicitly or explicitly, are challenged to make frequent changes in their construct of what constitutes this disease from beginning to end. Last, I want to factor into the aforementioned model the dynamic of situational ethnicity amounting to repetitively adjusted acculturation statuses.

## ETHNIC MINORITY LIFE, CHRONIC DISEASE, AND ADAPTATIONS

People cope with disease and disability in life by drawing on the foundational wellsprings of their culture to construct explanations and forecasts about their predicament (Henderson & Henderson, 2002; Kleinman, 1980; Kleinman, Eisenberg, & Good, 1978; Pfifferling, 1981). Cultural foundations include existential and cosmological beliefs about why we are here and where we are going. Vexing questions arise in the presence of chronic and debilitating disease including queries such as "Why me?" or "Why my loved one?" Looking into the future will involve more mundane yet very critical issues such as the economics and politics of one's life context relative to assistance with long-term disease and long-term

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coping. Additional cultural factors as basic as kinship systems and values of family solidarity can directly affect the nature of how, who, when, and where caregiving for chronic disease occurs (Henderson, 1987, 2009). Inexorably, end-of-life matters will eventually be confronted. Cultural concepts of religion relating to moment of death and mortuary practices may collide with legal codes of the dominant society and influence the entire process of death including anticipatory grieving, postmortem grieving, burial practices, and the ways in which the decedent's financial resources will be allocated or lost (cf. Henderson, Finke, & McCabe, 2004). Chronic disease may be the quintessential window into the machinations of a culture's capacity to meet the many social and behavioral demands of persistent sickness.

All people, consciously or unconsciously, use their cultural milieu to cope with all manner of life's difficulties. However, there are ethnic minority segments within larger populations that may experience chronic disease in the context of a persistent state of vulnerability because of the injustices common to minority life. Risk of exclusion and isolation of members of ethnic minority communities is heightened by behaving in ways considered deviant or nonstandard by the majority population. Protecting one's self, family, and community from the penalties of being seen as too different or too ethnic by the majority population are sufficient to motivate constant reassessments of social situations and cause a series of varied behavioral enactments calculated to achieve a better cultural and behavioral fit for the circumstances (Green, 1995; Helman, 2007; Tseng, 2003; Valle, 1989, 1994, 1998).

Within these factors and dynamics of ethnic minority life, evolve disease constructs that integrate vast numbers of elements into an explanatory model fitting personal and ethnic minority contexts. In the presence of chronic disease, there will likely be multiple forays into the biomedical environment as well as self-treatment and possible use of folk remedies. Differences between the culture of biomedicine and ethnic minority health beliefs and practices can be discomforting and only partly useful. Yet, many disease construct analyses do not adequately account for constantly changing symptoms common to degenerative chronic diseases and ethnic minority attempts at adaptations to negotiate the biomedical environment.

## ORTHOGONAL CHRONIC DISEASE MODEL AND DEMENTIA

The OCDM is currently a hypothesis stimulated by other empirical studies cited herein and my own in-person observations from decades of work with ethnic minority dementia caregivers and their clinicians. I attempt to bring forward the essence of this body of work and juxtapose them into a clockwork of interconnected biological, social, psychological, and cultural dynamics. I will use dementia as a "type" disease with which to ground the OCDM.

Efforts to clinically stage the many aspects of decline among the dementias has produced many schemas with numerous and varied stages corresponding to changing symptomatology. However, the boundaries between each stage are fairly arbitrary as reflected in the large quantity of staging schemas. Regardless of the arbitrary nature of staging ADRD, there is no question that there is progressive decline as reflected in worsening cognitive and, ultimately, physical function over time.

Although staging can be helpful in converting a wide-ranging set of symptoms into discrete (albeit arbitrary) compartments, degenerative progression produces not just a set of changing symptoms identifiable by clinicians. It also produces differing *kinds* of symptomatic presentations within an interactive cultural, social, and psychological context: the PWD-caregiver's lived experience of ADRD.

Caregivers have been studied for years with a focus on the burdens inherent to their caregiving tasks and their emotional adjustments to the sadness of watching their loved one's human socio-emotional and intellectual abilities slowly fade away. Caregiver burden studies have not, however, explicitly examined the caregiver experience in which they are, over time, confronted with a disease *which keeps its same name but radically morphs into a cascade of ever-changing new presentations*. I hypothesize here that the dynamic change of symptom patterns is experienced by caregivers as *categorically different kinds of diseases*. For example, the symptomatology of early ADRD is radically different than late stage ADRD. Over the evolving course of this disease, caregiver coping skills change drastically. Moreover, caregivers' conceptualization of that which constitutes ADRD shifts and reconstructs not only the caregiving tasks but also the entire experiential construct of what ADRD *is*. From caregivers' perspectives and experiences, they are not coping

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with one disease; they are coping with several "diseases." It is not one thing; it is multifaceted and multidimensional. From an ethnic minority perspective, there are unique cultural wellsprings drawn on in the early part of the ADRD experience relating to cultural constructs of causation compared to the latter part of the disease when caregivers will be experiencing a condition that requires them to draw on their culture's religious and cosmological values and beliefs because of their loved one's nearness to death.

Use of ethnic minority precepts to describe ADRD is suppressed by broad overreliance on the biomedical model. From the biomedical perspective, caregivers are told that there are neurological pathologies taking place that cause declines in cognition. This typical discourse causes caregivers to focus on biomedical precepts of organic causation for this disease and its progressively worsening clinical symptomatology. However, the day-to-day caregiver experience is one in which neuronal depopulation and imaging of the shrinking brain has little relevance to the lens through which they see their loved ones decline. Caregivers' interpretations of the progression of the disease are based entirely on their experience of the patient's behavioral aberrations, not that day's increase in plaques and tangles.

The elements of the OCDM for understanding the dynamics of dementing disease is shown in the dynamic culture and coping map (Figure 2). The arrows in Figure 2 show progression in two directions: (a) degenerative progression in stages as shown by horizontal arrows and (b) caregivers' cognitive, emotional, and cultural adaptations within each dementia stage as shown by vertical arrows.

In the top row in Figure 2 are three stages of clearly symptomatic dementia identified as "early," "mid," and "late" stages. As noted earlier, there are many different staging schemes for ADRD. The Mayo Clinic uses a three-part staging schema similar to that shown in Figure 2 (Mayo Clinic, 2013).

Along the second row are a series of "caregiver contemplations" that address a multitude of important life issues that naturally emerge as the disease progresses. Along the third row are the "ethnic minority traditions" that provide the cultural foundations of their lives that constitutes their framework for adaptation and proper behavior under duress. Ethnic minority caregivers look for ways to adapt and cope with this chronic condition whether consciously or unconsciously acknowledging such acts. In the last row are bidirectional arrows showing that all interactions of ethnic minority families are performed with an assessment of each social situation and a selection from their behavioral repertoire to best fit that specific circumstance.

Beginning with the early dementia stage, there are the main initial symptoms listed and issues of activities of daily living with which the caregiver must now assist the PWD. Below that cell is a list of Caregiver Contemplations associated with early-stage symptoms and behavioral problems. For example, caregivers often wonder what has caused this condition to befall them. There is also the issue of disease definition that can include the biomedical concepts as well as ethnic minority concepts. Caregivers also will look to cultural constructs of similar kinds of conditions that they have heard about or have known from their own life experience to further refine their construct of what is causing the PWD's problem. Below that cell are ethnic minority traditions. These are the ethnic minority cultural sources that are very basic to one's life experience, assumptions, and overall ethos of their lives. There are beliefs about the nature of disease in all of its manifestations. Also, there will be health beliefs that serve to define and interpret the nature of mental conditions and behavioral aberrations.

Continuing with the examination of Figure 2, mid-stage dementia shows that the PWD's symptoms have now progressed to having significant difficulty with communications. Specifically, there will be problems with name finding, forgetting personal names, including those of close family and friends, and syntactical confusion. There is also the dangerous problem of getting lost, and there is now more need for caregivers to help PWDs with basic issues of getting dressed and eating. Below that cell are Caregiver Contemplations associated with mid-stage dementia. This includes the refinement of caregiving roles. Caregiving roles can include not only who in the family does what kind of caregiving tasks but also when and where. Also, gender is often a factor in the discharge of caregiving tasks and, most often, such tasks are assigned to women in the household. There's also the management of the caregiving process that is a function of family dynamics and ethnic minority normative sets about how to behave under duress. There may be family members who are assigned to make arrangements for caregiving and manage the accomplishment of necessary caregiving while not actually doing those tasks themselves. During this time, there is also a developing deep awareness that this problem is truly a chronic and worsening one. Such an awareness can also lead to depression among the caregivers because they may now feel hopeless about failed fantasies of "beating" this disease with medications or discovering that it was a mistaken diagnosis. Below that cell are the ethnic minority traditions, which will be associated with coping and providing answers for the caregivers' numerous contemplations. These include ethnic minority kinship patterns and family values of solidarity that relate to care for dependent people, particularly older adults. There may also be decisions made about

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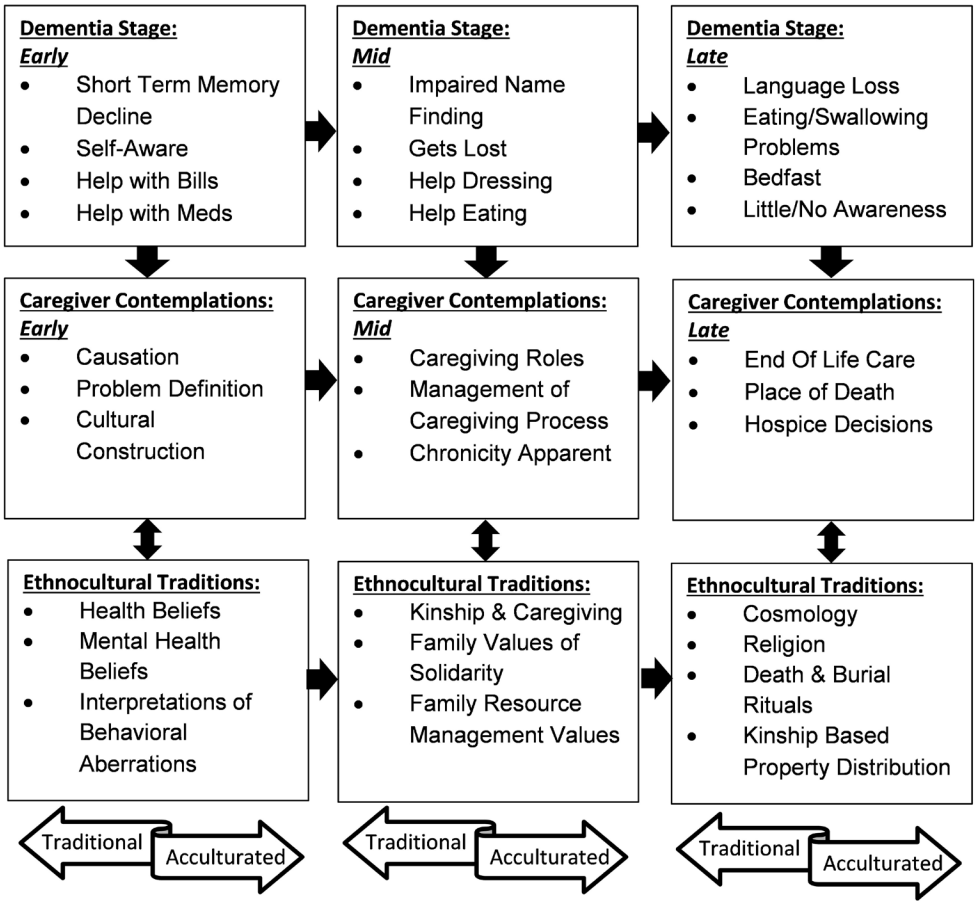


**Figure 2.** Dynamic culture and coping map.

caregiving related to what resources the family may have both in terms of human resources and economic resources. The question will be how to organize the use of these resources in a manner consistent with their ethnic minority traditions.

In the late stage of dementia (Figure 2), the PWD's behavior now has become severely impaired. The ability to speak is nearly lost, and there are basic reflexes that are now failing that cause difficulty with eating because of swallowing problems. There will likely be incontinence of both bowel and bladder. Cognitively, the PWD has only slight to nil self-awareness in the final stages of the disease. Below that cell are the caregiver contemplations appropriate to the mentioned symptoms. At this time, end-of-life care will provoke several questions for the family in their cultural context. For example, there may be concerns about where the death will take place and the possible wish to avoid hospitals as a place of death. There may also be discussions about hospice because it can be done entirely in the home most of the time. Below this cell are the ethnic minority traditions that are used for coping including the reference to the basic cosmology of the ethnic minority group. This relates to religious beliefs about the afterlife and about those who are assisting with caregiving. In addition, death and burial rituals will be commonly addressed and brought forward to discussion for future action. Kinship-based property and resource distribution that is embedded in ethnic minority traditions becomes an important factor for discussion at this stage of dementia.

Beneath each of these columns is a reminder that these ethnic minority families are conducting their lives as caregivers who are interacting with the biomedical community as well as the larger majority community and expending emotional effort as they cyclically change positions along the acculturation continuum. As Figure 2 shows, the ethnic minority experience of dealing with dementia in a family member is a complex, ever-changing, ethnic minority experience.

## VIGNETTE

This multistage vignette is of ADRD in a Latino family living in the southeastern United States. All names are pseudonyms. The

interview data stem from an ethnographic research project funded by the Administration on Aging in the United States to the author. The purpose was to develop ADRD support groups in the Spanish-speaking communities in two cities 322 km (200 mi) apart. In the process of conducting the targeted ethnographic survey among the communities and families in two cities, several case studies were developed (Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993). From the late 1980s and for the next decade, the effects, analysis, and resulting publications were disseminated (Henderson, 1990, 1992, 1994, 1996; Henderson & Gutierrez-Mayka, 1992; Henderson & Whaley, 1997).

The family is composed of a 68-year-old man who is hospitalized with a diagnosis of vascular dementia. The caregiving network included his elderly mother-in-law, his wife, an adult daughter, and two adult sons. All lived within the same community. This vignette will chronologically follow the family caregivers as the PWD experiences the cognitive and functional declines of dementia over time.

## Early-Stage Dementia

Mrs. Garcia discusses the early stages of her husband's dementia and begins to tell of a specific circumstance. She begins by explaining a value within the Latin community, "I tell you one thing about the Spanish, they will get very upset about someone who is crazy or does crazy things." Early in the disease Mrs. Garcia describes a time when her husband would urinate on the living room floor. Mrs. Garcia was mortified by his behavior and reports that she tried to create a façade of household normalcy to her neighbors and this would include her children and mother-in-law. She goes on to say, "How can I tell my family not to bring a girlfriend or boyfriend here because the house smells of urine?" She also adds that there was a loss of friends that they had for many years because, as she says, "fear of the disease."

Mr. Garcia's behavioral aberrations did not stay within the confines of their home. One night, Mrs. Garcia awoke to find that Mr. Garcia was no longer in his bed. As she searched the house to no avail, it became clear that Mr. Garcia was somewhere outside. Mrs. Garcia ran outside looking up and down the street, did not see him, and got in her car to drive around the neighborhood. Not finding him that way either, she finally had to knock on the neighbors' doors and enlist their aid in the search. At last, a neighbor found him about 2 miles away walking in only his underwear and with abrasions on his feet.

*Kinship-based property and resource distribution that is embedded in ethnic minority traditions becomes an important factor for discussion at this stage of dementia.*

***Comment.*** Mr. Garcia's early stage dementia was marked by the usual symptomatic pattern of memory loss and confusion, a large number of medications, and need for assistance with transactions related to bank accounts and other financial matters requiring even simple calculations. Latin values of stigma and fear of ADRD behavioral aberrations were derived from their cultural construction of disease and its definitions of "crazy behavior." The family's beliefs about mental health problems led to social mortification, a sense of humiliation, and a wish to conceal her husband's condition because of his publicly observed behavioral aberrations related to brain disease. The family would often tell others that Mr. Garcia's behavioral aberrations were because of an "organic" problem with his brain. This message was intended to neutralize the potential for others to postulate that the Garcia family was possessed of *mal de sangre* (bad blood), which would be considered a defect internal to the family and suggesting some inherent, pernicious flaw with which this family was secretly afflicted (Escobar & Randolph, 1982). Secretly, that is, until Mr. Garcia's behavioral aberrations became troublesome and public.

## Mid-Stage Dementia

As Mr. Garcia's vascular dementia worsened to mid-stage, they sought a clinical diagnosis that required testing and short-term hospitalization.

The Garcia family crowded around the bedside when the neurologist came to deliver the information to the family. They were told that Mr. Garcia had vascular dementia, he would continue to worsen, and there was no treatment that would stop progression of the condition. The physician told them that nursing home care was the primary recommendation for the best caregiving action.

Hearing this information, Mrs. Garcia led the daughter into the hospital hallway away from her two brothers. The daughter was told by her mother that, "Now it is up to us to provide the best of care . . . " for Mr. Garcia, but at home, never a nursing home. However, the daughter immediately recoiled on the realization that of all the siblings, it would be her and not the adult brothers who would be asked to provide the primary burden bearing assistance to her mother.

One of the brothers lives on the same block as his parents. However, Mrs. Garcia states that he is unable to provide the hands-on care to his father because it is too upsetting to him. The other brother lives about 30 minutes from the parent's home and is considered to be overburdened by his job, wife, and children. Their sister who has been designated as the primary assistant to the mother also works full time, has children, is single, and lives about 15 minutes from the parents' home.

***Comment.*** Mrs. Garcia was an older adult who had grown up in Cuba and later had migrated to the southeastern United States. However, the daughter was born in the United States and had a different idea of gender role performance when there was a male likewise available to provide care. Mrs. Garcia could not understand her daughter's negative reaction. Nonetheless, as Mr. Garcia was transferred home with his care continuing there, it was Mr. Garcia's wife and daughter who were the on-call caregivers.

This case of contested role performance in caregiving was largely attributable to ethnic minority cultural variation in gender role expectations across generations. The conversation noted earlier was part of the effort to manage the caregiving process following the value system and expectations of their ethnic minority background. Furthermore, it was immediately apparent that the husband would no longer be expected to improve and that his behavioral aberrations would continue for the remainder of his life. The chronicity of his condition was definitely established.

The kinship and caregiving value system also dictated against the transfer of Mr. Garcia to a nursing home as was recommended by the neurologist. Their sense of family solidarity and demonstration of love and compassion for family members operated against placement in an institutional long-term care setting. As another member of the support group said about avoidance of nursing home placement (Henderson, 1997, p. 427), "Latin people, we are very stupid [to not use nursing homes]"; yet, she continues with her reason: Nursing home placement would "bury him before he dies."

Also apparent is that although at the bedside, the ethnic minority family acted out the expectations of a more acculturated family in the presence of the neurologist. There were no complaints against the nursing home recommendation, and there was total acceptance of the veracity of the diagnosis. Mrs. Garcia metaphorically slid along the acculturation continuum from highly acculturated to more traditional and literally moved to another private location to voice her ethnic minority value system of proper caregiving done by the women at home until the end.

### Late-Stage Dementia

Mr. Garcia's late-stage dementia was played out at home in accordance with their ethnic minority values. He died a little more than 3 years after his diagnosis. Discussions of end-of-life issues revealed that the topic of funeral arrangements cued one of Mr. Garcia's sons into action. This son was the one who was too over worked and too far away to help with caregiving. The funeral, however, would be planned by him and would be done in a way to ensure that the family's reputation and status within the local community was preserved or even heightened. Specific discussion was made about the intent to show that no funeral expense was too great for Mr. Garcia.

The odyssey of Mr. Garcia's multiyear vascular dementia provoked soul-searching musings during end-of-life discussions among the family during which Mrs. Garcia wondered out loud if she was being punished for some past sin. She appeared depressed. Holding her head in her hands, she stared into space. The adult children assured their mother that this was a physical disease and not the result of any past improper behavior of hers.

*Their sense of family solidarity and demonstration of love and compassion for family members operated against placement in an institutional long-term care setting.*

***Comment.*** The funeral was seen as a public event in contrast to the in-home caregiving done out-of-sight of other members in the community. Consequently, the preservation or even elevation of family status in the context of the Latin community became very important with the funeral as the vehicle to accomplish this. The funeral was also expected to be held in a Catholic church and burial in a specific Catholic cemetery used by many from their family's original region of Latin America, not just anywhere. Part of the son's role performance responsibility as a Latin male was to be certain that all matters related to his father's estate and property were properly distributed across the family.

Cosmology and religion figure into Mrs. Garcia's end-of-life ruminations. She speculated that she had committed some egregious sin that resulted in this disease and its caregiving enervation. Her explanation of why *she* was visited with years of caregiving to a husband with dementia hinted at some personal malfeasance and departed from biomedical, neurodegenerative disease explanations that could include genetics, hypertension, smoking, and other empirical explanatory comorbidities as risk factors. Her musings were rooted in her child and adulthood religion, made perhaps more strident because of her Latin roots from Spain and its colonial intrusion into Cuba with European-style Catholicism. The weaving of intimate, soul-searching spiritual queries into the context of ethnic minority caregiving is seldom heard by clinicians but can be the main sources of anxiety, despair, and caregiver exhaustion.

## SUMMARY

The ethnic minority PWD and the caregivers do not occupy one single "ethnic position" on an acculturation scale. The expression or suppression of ethnic minority values, beliefs, and behaviors varies based on differing situations, including ones related to the medical, religious, economic, and other disease-management needs. As ethnic minority populations increase in number and longevity, the prevalence of chronic, progressively degenerative disease will rise.

Using the OCDM will create a more comprehensive and flexible cultural construction of disease model and will assist in understanding how to respond best to relieve the suffering of all.

Interconnections of biocultural phenomena are not only composed of domains of biophysical and sociocultural elements of life but are also most comprehensible by the inclusion of their temporal aspects. Life as well as disease is not static. "Static interconnections" may be nearly oxymoronic. By analogy, the increased explanatory power of longitudinal studies over cross-sectional ones is caused by analysis over long periods of time.

The OCDM is an effort to bring the temporal aspects of life, health, and disease to the continually evolving cultural construction of disease model. Nowhere else is understanding the interactive effects of cultural context plus time more important than in neurodegenerative diseases such as ADRD. Over time, neurodegenerative disease morphs from one "face" to another. No sooner does one face of ADRD become known to caregivers than it shifts to the face of a stranger who they must meet anew.

*As ethnic minority populations increase in number and longevity, the prevalence of chronic, progressively degenerative disease will rise.*

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