Substantive Articles
Organ Harvesting from Anencephalic Infants: Health Management Over a Sinkhole
Andrew J. Alatis................................................................. 3
Outreach to Ethnic Minorities with Alzheimer’s Disease: The Challenge to the Community
Ramon Valle, Ph.D............................................................... 13
Epidemiology, Diagnosis, and Management of Alzheimer’s Disease and Related Disorders:
  Implications for Minority Populations
Kathleen Smyth, Ph.D., Peter J. Whitehouse, M.D., Ph.D.,
Michael Rust, M.Div, and Jeffrey Kahana................................. 28
Alzheimer’s Disease in the Context of Black (Southern) Culture
Artwood D. Gaines, M.A., Ph.D., M.P.H................................. 33

Topics of Interest
Participatory Management in Nursing as an Alternative to Traditional Management
Marilyn Kabb, R.N., M.S.N., O.C.N........................................... 39
Cost Control and the Clinician
John P. Rovers, Pharm.D., R.Ph........................................... 45
An Analysis of the Formality of Relationships Between Hospitals and Home Care Providers in
Arkansas
William B. Olson, Ph.D. and Karen K. Olson, Ph.D...................... 48
Trends in Long-Term Care for the Elderly
Norman Cates, Ph.D........................................................... 50
State Interference in the Refusal of a Jehovah’s Witness to Accept a Blood Transfusion
Vivian Riesenman............................................................... 57

Interview
Helen VerDuijn Palit on City Harvest, Inc.
Ruth Charbonneau............................................................ 68

Cases and Statutes in Review
Physician Not Liable for Failure to Disclose Risks and Alternatives to Third Party......................... 70
Recovery of Medical Damages for Unplanned Pregnancy................................. 70
Court Reaffirms Need to Protect Patient Confidentiality During Disciplinary Actions Against
Physicians................................................................. 70
Changing the Rules of Negligence............................................ 71
Absent a Consensual Relationship, No Malpractice........................................ 72
The Law Allows for Common Sense: Expert Testimony on Standard of Care Not Always Necessary........ 73
Malpractice “Crisis” Legislation Held Unconstitutional................................. 73

Book Reviews ....................................................................... 75

Instructions for Contributors ..................................................... 77
ALZHEIMER’S DISEASE IN THE CONTEXT OF BLACK (SOUTHERN) CULTURE

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Abstract Medical and lay interest in Alzheimer’s disease has increased dramatically in recent years. A newly developing aspect of this overall interest centers on assessing the nature and impact of Alzheimer’s in the context of minority populations. This article seeks to add to the scant literature on culture, ethnicity, and Alzheimer’s disease. The paper considers clarification of some key terms “culture,” “ethnicity,” and “race” as an important initial step in placing Alzheimer’s within any cultural context. The focus of the present article is southern (American) culture and its most common northern representative, black culture. The paper shows that the meanings and significance of symptoms associated with Alzheimer’s are likely to be interpreted in terms of a folk medical system’s models of illness, which is described, and not in terms of biomedical models. The cultural contextual basis of symptom assessment, the cultural meaning of symptoms and their implications for help-seeking are discussed as are features of family social organization in black southern culture which have implications for care-giving and care-burdens.

INTRODUCTION

Culture, Ethnicity, and “Race”

Before discussing Alzheimer’s disease in the context of black culture, it is necessary to define key terms, terms which cause much confusion in lay and scientific subcultures in America. These key terms are “culture,” “ethnicity,” and “race.” In contemporary social and cultural anthropology, the social science which studies culture, culture is seen as a system of meanings embodied in significant symbols. Symbols serve as vehicles for cultural conceptions. Symbols may be words, acts, gestures, events, even illness symptoms. No human being can exist without culture and the orientations to self and other which cultures provide and sustain; in fact, the human animal is made human by virtue of membership in a particular cultural group.

Though all people may be said to have an ethnicity as well as a culture, the terms culture and ethnicity are not synonymous. Cultural ideas are those which individuals or groups regard as ultimately true, real, and “natural.” However, this level of assumption is usually unconscious and involves notions of self and person, temporal orientations, normative structures, and orientations relative to spatial and other (e.g., spiritual) dimensions. Ethnic identity, however, is a social self identity and is subjective and conscious.

Ethnic groups are groups perceived by self and other as having a sense of a common past and, it is believed, they share particular characteristics. The maintenance of the group is based upon the maintenance of boundaries based upon subjective criteria, criteria often thought to be objective. Individuals claim membership or are ascribed membership in a group based upon relevant criteria. These criteria vary from group to group in dramatic fashion and, depending on the context, may involve religious ideology or practice, place of birth or residence, occupation, putative physiognomy, real and/or fictional descent, a belief in a common past or esthetics. Finally, ethnicity involves a past, rather than a future, orientation.

Different ethnic groups may share the same general cultural tradition as, for example, in the case of Hispanic groups such as Mexican-Americans, Puerto Ricans, and Latin American ethnic groups. Though in terms of the latter, the various distinct Latin American Indian ethnicities must be excluded.

National identities may or may not also be ethnic identities. In France, most people in Paris are French nationals and French ethnics. But while the people of Alsace, a province in eastern France, are French nationals, they are not French ethnics; they are Alsation ethnics. The same situation prevails for the Bretons, the people of Brittany in western France. In America, ethnic Chicanos, Italian-Americans, Chinese-Americans, and others are American nationals, but they are not American ethnics (WASPs).

To distinguish culture and ethnicity from “race,” we note that the latter is an American cultural concept, not the biophysiological reality it is thought to be. Human groups are not naturally divided nor are they scientifically conceptually divisible into races, each with unique, distinctive characteristics which are replicated in each generation. The total lack of relationship between putative “race” and behavior (the latter in the forms of language, religion, and other cultural components) was clearly demonstrated by the father of American anthropology, Franz Boas, in the early part of this century. He also demonstrated the complete lack of validity of the lay and scientific notions of biologically distinct groups corresponding to one or more of the various racial classificatory systems.

Recent research shows biologists and anthropologists that “race” is a cultural construction used in the United States and a few other cultures and that the term often has different meanings when used to classify people. The term is used...
here with quotes to indicate that it is a folk, or culturally specific ethnographic term.

The biological concept of "race" has thus become unacceptable to social-cultural and physical anthropologists as well as to biologists.11 This cultural, rather than biological, basis for the concept of race has long been noted by UNESCO13 and was recently noted in the U.S. Supreme Court ruling expanding the basis for suits of discrimination based solely on putative "race" to include ethnicity, a term the Court uses to encompass cultural groups said to belong to the same "race."14 It is also important to note that the referent of an ethnic label, e.g., "Creole," may change over time. Also, members of such groups are never homogeneous in thought or behavior. Rather, cultural expressions may be seen as heterogeneous and as lying along a cultural continuum.15-17

People in the United States who are labeled "black" do not share a common biological heritage, nor do they have common historical experiences, political or economic relations or positions. The individuals lumped together and seen as homogenous form a group only in the minds of many Americans; the "group" has no objective existence. In America one tends to ignore the fact that "blacks" have, aside from those of West African ancestry (as distinct from some generalized "African" ancestry), much European ancestry. For those people who came to the southern plains and southwestern parts of the America, one also finds significant Native American ancestry. With such extensive mixing of a specific population from West Africa (which itself has already interacted with Mediterranean and Middle Eastern groups), the suggestion that "blacks" constitute a distinct, unitary race is quite fanciful, or, in this case, cultural. Also, the belief that people of West African ancestry in the U.S. have a common history and experiences in this country is likewise without evidence.

One must note, too, that the people of Africa vary radically not only in culture (i.e., religion, kinship systems, cosmologies, theologies, economic and political systems, legal systems, etc.) but also in physical appearance. One is struck, for example, by the lack of resemblance between, say the Pygmies and their next door neighbors, the Bantu, or between the people of West Africa and those of the Nile area in East Africa. The dean of physical anthropologists of Africa, Jean Hiernaux, has shown that there are in fact 1,000 biologically distinct groups in Africa itself.15 Races, then, have a cultural reality, not an empirical, social, or physical reality. This cultural reality of "race" is, in fact, of recent origin and is properly termed an idea of modern times.16

In America, the cultural fiction of "races" and their putative distinctiveness is maintained through the cultural practice of assigning people of mixed ancestry to one or another group, depending upon the number of "races" one believes exist, and imputing behavioral or ideological characteristics to the members of the groups thereby created. This set of practices both sustains racist ideology and replicates the essence of a caste system of social stratification such as is found in India and Japan.17

Alzheimer's in Cultural Context

Black and Southern Culture: the Meaning Context of Alzheimer's

What is regarded as black culture in America may be seen to be part of what is now called Southern (American) culture. The culture is distinctive in its beliefs and practices, which include a tradition of authoritarian religion, familism, male/female antipathy, parochialism, and an honor and shame complex. Its social organization is likewise distinct and includes hierarchical social relations, extended family organization, a coincidence of political and religious leadership and other features. Bearers of southern culture include southern "whites." Thus a common culture is held by the two major southern ethnic groups, "blacks and whites," usually seen as distinct "races." This cultural commonality has been recently recognized by the compilers of the Encyclopedia of Southern Culture now in preparation at the University of Mississippi. But one must recognize variation in any culture area—in this case, such as the Delta, the Territories, and Piedmont variations. The Southern tradition is largely based on the cultural/religious traditions of the Mediterranean culture area.18-20 The common culture of southern "blacks" and "whites" highlights the lack of utility of racial classifications habitually employed in American science and society.19-21 Also noteworthy is the misleading application of the term "black" to immigrants from such disparate cultures as Ethiopia, Jamaica, Cuba, Haiti, and Puerto Rico.

Within the Southern cultural context, Alzheimer's disease, and any other diseases recognized by medicine, present problems of perception and diagnosis. These problems derive from pre-existing cultural conceptions and social practices which form the context within which symptoms gain their meaning and significance. And, in terms of the locus of the beliefs and practices described below, it is important to recognize the regional cultural context. Hence, the beliefs relating to Alzheimer's may be expected to be held by many "whites," those who share in the regional culture, and to be lacking among many "blacks," those who do not share the southern regional culture.

Folk Theories of Disease Causation

In this cultural tradition, health is viewed as the result of a maintenance of balance. This is true in other cultures as well, e.g., Chinese, Japanese, Mediterranean, and classical Greek culture.22-24 With regards to the diagnosis and treatment of Alzheimer's disease, the folk medical etiological concepts of "natural" and "supernatural" causation are likely to come into play.25-26 Supernatural illnesses are distinguished from natural illnesses by symptomatology or the social context of the victim. Each illness has an expected symptomatical picture. If expectations are not met, the illness will often be assumed to be supernatural in origin.27 Supernatural diseases are thought to result from three sources, witchcraft, God, or the devil.
A folk notion of illness as divine retribution is found in Southern culture. This cultural notion sees certain diseases as consequences of earlier, improper behavior. As such, certain diseases or conditions are “to be expected,” and are thus culturally sanctioned and, in a sense, justified.

“Poisoning” is a common fear in Southern/black culture. Hence eating at the home of “strangers” or in a “strange” restaurant is believed to put one at risk for poisoning and subsequent illnesses, the symptoms of which may overlap with many disorders differentiated by biomedicine.

Witchcraft beliefs are found throughout the South and illness and death are believed to result from the malevolent intentions of others. “Hexes” may be “put on” individuals by malevolent others. This “root work” or “voodoo” is done through the use of herbs or roots, hence the term “root work.” Certain individuals are able to heal in the tradition and may use roots and are thus known as “root doctors.”

A supernatural illness can result from the fact that past sins may be punished. Thus, God is seen as an agent of both good and bad, as in the case of disease. The devil is also seen as a possible agent in unnatural disorders, claiming the uncautious and or the unwary.25,26

**Folk Illnesses and Alzheimer’s**

There are a number of folk illnesses that are found in Southern/black culture that have some implications for Alzheimer’s. Folk illnesses are those that are specific to a particular culture. Such illnesses are unique because they embodied culturally specific conceptions of life, health, the nature of persons, and interpersonal relations.26

One such Southern/black illness is “Worrination” or simply “worry.”25 It is a combination of worry and stress. Worry, it is thought in the culture, can damage the unborn and/or cause brain damage. And it is believed that one can actually overuse one’s mind to the detriment of the brain. That is, thinking “too much,” “too much head work,” is believed to be damaging to the brain. Given this folk disorder, culture members may attribute growing cognitive deficits to this folk illness and, having diagnosed the case, fail to seek assistance.

Another folk illness is “falling out.”26,27 Falling out presents as loss of consciousness and a physical collapse. Victims, however, are rarely hurt when they lose consciousness and collapse. In medical circles, falling out is often confused with epilepsy, head trauma, or other neurological problems. It is possible that certain manifestations of Alzheimer’s will be interpreted within this illness idiom.

“High blood” is a condition in which the blood is not flowing normally through the body; it is “thicker” or “sweeter” and, therefore, believed to be stagnating in the higher areas (head, chest) of the body. High blood, it is believed, can cause cerebral problems, as when the pressure of “too much blood” “bursts blood vessels” in the brain.27 Someone with Alzheimer’s, therefore, may be diagnosed by friends and relatives as suffering from some stage of high blood.

“Low blood” is another folk illness. It is the opposite of high blood in that low blood is believed to be abnormally “thin and sour” and to collect in the lower extremities. A loss of vitality, enthusiasm, or focus is symptomatic of this disorder and, as such, is a likely candidate for confusion with Alzheimer’s symptoms.

“Spells,” is a folk condition which may affect a person. Though not an illness per se, it may have implications for the recognition of Alzheimer’s disease. Spells appear as periods of unusual consciousness. The term encompasses cases where someone is extremely angry or otherwise upset and also includes fugue states, trances, and waking visions (for instance, where one is awake and believes he or she sees a deceased relative). In this cultural context, as in China, individuals can appear to be psychotic for brief periods of time, though normalcy returns in a matter of minutes. Since a person afflicted with Alzheimer’s may experience fluctuations in cognition or mood, in this context, such symptoms may be seen as indicating that a person is merely “subject to spells.”

Impairments in functioning and motor activities likewise may also take on a different meaning in Southern culture. There one finds a wide semantic net cast by the folk illness label “arthritis.” Though this disorder is terminologically identical to a biomedical disease entity, it is conceptually distinct from it and encompasses symptoms not seen by biomedicine as reality. Because of the meaning of arthritis, increasing functional disabilities may be attributed to the folk illness. The folk diagnosis may thus conceal neurological deficits by misattributing them to “expected” (because of increasing age) and justifiable (because of past sins or a wild life) “arthritis conditions.”

It should be noted that these folk illnesses (hexes, worrination, falling out, high blood, spells, arthritis) are not descriptions of symptomatology but are diagnoses of illnesses within Southern/black folk medicine. Thus, there are several distinct possibilities in the medical subculture for labeling what biomedicine labels Alzheimer’s. There exists no single nosological entity within Southern/black folk medicine for biomedicine’s Alzheimer’s disease entity. As a consequence, we can expect symptoms to be interpreted within the existing folk nosology.

The consequences of a folk medical diagnosis may be that help-seeking and treatment of other action relative to Alzheimer’s may be greatly delayed. Even when psychotic features develop, they are likely to be interpreted within an idiom of divine punishment for past sins.

Some of biomedicine’s chronic diseases, e.g., hypertension and diabetes, are seen as resulting from an improper diet, rather than from histopathological or endocrinological problems. Arthritis itself is often seen as a result of a wild youth during which an individual allowed him or herself to be “exposed” to the elements causing an accumulation of “cold” which later causes the functional problems.28,29 Most importantly, all diseases are believed to be self-limiting. The category of “chronic” diseases is
unformulated in Southern folk medicine. If a disease is not cured, the explanation lies in the incompetence of the doctor, the inappropriateness of the treatment(s), or a condition’s supernatural etiology. It is this belief complex which makes religious healing reasonable in the cultural tradition.

As a consequence of these beliefs, there is a high degree of noncompliance in treating chronic illnesses. In cases where a person is seen by a physician, his or her level of compliance may be quite low and, since there are recognized treatments for the folk illnesses, these may be used instead of or in conjunction with whatever biomedical treatments may be employed. These folk treatments may or may not influence the symptoms, masking or exaggerating them, and they may or may not positively or negatively interact with biomedical interventions.

Cognition and Affect in Culture

An important potential feature of culture which interacts in a specific way with Alzheimer’s is the psychological orientation of a particular cultural tradition. Some cultures greatly emphasize cognitive functioning and see it as distinct from the affective dimension of the psyche. This is the cultural orientation of American (WASP) culture and of biomedicine, the professional medical system grounded in that cultural tradition. That cognition and affect are not “naturally” but rather culturally differentiated is clearly shown in a number of recent psychiatric anthropological works on this issue. Individual in such a culture achieve and maintain a sense of self-worth through the display and nurturance of cognitive or intellectual abilities. There is some indication that those of this cultural orientation will often early perceive signs of change due to Alzheimer’s and seek diagnosis before these changes are even clinically detectable.

Other cultures, such as Southern culture, are more concerned with emotions and role expectations. In Southern culture, as in Indonesia, one notes that cognitive decline or dysfunction is not as important as failure in role functions to significant others. Southern/black culture places a much greater emphasis on affective functioning than in cognitive functioning, as might be surmised from the presence of a folk disorder caused by “thinking too much.”

In such a tradition there is less emphasis on cognitive clarity and on displays of intellectual mastery. Rather, cultural emphasis is placed on proper affective relationships and on the fulfillment of proper role obligations. Limited preliminary data from neurologists suggests that for this reason, help is sought for individuals, much, much later in the course of Alzheimer’s than is the case for WASP or Yankee ethics. This same affective emphasis is likely to be found among Mediterranean ethics as well (e.g., Italian, Greek, French, Spanish, Middle Eastern or North African ethnicities).

The emphasis on cognitive abilities and their cultural value will doubtless have an impact on the course of the disease. Those who greatly value cognitive functioning are at risk for great psychological trauma and even depression as a result of a loss of self-esteem and the crushing blow to one’s very conception of the good life.

FAMILY, SOCIAL ORGANIZATION AND ALZHEIMER’S

Related to issues of late or early detection and the personal impact and meaning of Alzheimer’s are the issues related to diagnosis and the burden of care. This latter issue is best understood in the context of family social organization in Southern culture.

A strong notion of familism, as in the Mediterranean cultural area, is noteworthy in this regard. In the WASP culture, kinship is defined by biological roles and legal relationships which only appear to be “natural and logical.” Southern/black culture has a different kind of kinship system.

Unrelated individuals may be added to the kinship system, and receive terms of consanguineous (blood) relatives such as aunt, uncle, brother, sister, or, most commonly, cousin. Conversely, consanguineous kin can be severed from one’s kin group if they fail to fulfill role expectations. Thus, unlike WASP kinship, Southern kinship can drop brothers, sisters, mothers, and fathers and replace them with non-blood relatives, whom anthropologists call “fictive” kin.

Within the kinship group, role performance is of utmost importance as are affective ties. People can adequately perform their roles within the kinship system, even when quite disoriented outside of it. Therefore, a person with Alzheimer’s disease may be able to function in the kinship system for a longer period of time without causing alarm than would be the case where one’s place in a kinship universe is not determined by role performance but by notions of law (in-laws) or biology (father, mother).

The kinship system generally involves many people and is an extended family system. No single form of family may be said to exist in black or the wider Southern culture. The emphasis on the family and the depiction of the “importance,” “strength,” “centrality,” or even “weakness” of “the family” in Southern/black culture are actual expressions of the culture’s familistic emphasis, and not references to any one form of family organization. Because of this familism, one may expect members of this tradition to have more people among whom the burden of care may be spread than in a nuclear family context. It is not uncommon for three or more generations to be co-resident. As well, individuals may be added to the household as family members even though they are not biologically related to other household members.

While the extended family is an important unit in black culture, it is not necessarily a co-resident, domestic unit. Elements of the extended family may live nearby and visit daily, as is found in France. But kinship is yet the key organizing principle in Southern/black society. As a result there is a reluctance to join voluntary associations in both the Mediterranean and Southern traditions.

Clubs or other associations are not well developed in the South, as
Alzheimer’s disease as a cultural as well as biomedical phenomenon. This must be an appreciation by health professionals of the distinct ways disease can have an impact upon particular ethnic, cultural, and social arrangements, and they must develop clearer understandings of the nature and character of ethnic, cultural, and national groups themselves. Anthropological understandings of culture and identity must replace “common sense,” and therefore culturally formed and biased notions about social identity and group affiliation.

Health care workers must recognize that the symptoms of Alzheimer’s disease (or any other disorder) will be interpreted within particular cultural contexts—contexts which differ significantly from the cultural context of biomedicine. It is in these varied cultural contexts that symptoms acquire meaning and motivate or fail to motivate remedial action. A process of negotiation must be undertaken regarding the clinical and social reality of Alzheimer’s disease between caregivers and care receivers. Such negotiations of meaning and clinical reality, to be successful, must necessarily include cultural understandings in case assessment, education, treatment, and management.

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SUMMARY AND CONCLUSIONS

There are major educational needs in the Southern/black community related to Alzheimer’s disease. But there is likewise a great need for health professionals to recognize

The extended family in the Southern/black ethnic community can allow caretaking to be shared among a larger group of individuals. A whole range of people can be mobilized to respond, so the burden can be spread. The extended family can be a “therapeutic/managerial community.” And the church, too, has a role in management in Southern/black culture as it is often a major resource for illness problems from alcoholism to mental illness.

Another cultural difference is the fact that the Southern/black culture is permeated by biblical, ultimately Mediterranean, notions of universal truths. Because of this ideology, older people are seen as more valuable because longevity is viewed as a means of accumulating truths, as is found in France. Children, it is believed, will never know as much as their parents, because they have not lived as long, and thus have not accumulated as many truths. In this tradition, as in the Mediterranean tradition, the elderly can have a value not found in WASP culture and as a consequence are not as readily extruded from Southern or Mediterranean cultural groups as from the WASP ethnic context. Aside from the diagnostic differences and the reduced emphasis on cognitive functioning, the value of the elderly may play a role in reducing the numbers of people from this tradition seeking help from biomedicine.