
Cultural Aspects of Dementia

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ABSTRACT: This paper critically reviews current knowledge regarding culture and dementia in order to identify unanswered questions in the field. Medline was searched from 1993-2000. One hundred nine articles were identified, of which 59 were critically reviewed, augmented by additional references from experts and by books. Limited research evidence was identified in four areas: 1) the recognition of dementia across cultures 2) cultural specificity of screening tools 3) identification of differences in risk factors, incidence, onset and prevalence across culture 4) culturally related issues in decision making about management. Implications for research and practice are described.

RÉSUMÉ: Aspects culturels de la démence. Cet article révisé de façon critique les connaissances actuelles sur la culture et la démence afin d'identifier les questions pour lesquelles il n'y a pas de réponse. Une recherche documentaire a été effectuée dans la banque de données Medline de 1993 à 2000. Cent neuf articles ont été identifiés dont 59 ont été révisés de façon critique, complétés par la recherche des articles pertinents cités en référence et consultation d'experts dans le domaine. Quatre aspects ont été identifiés sur lesquels on retrouve peu de données de recherche: 1) la reconnaissance de la démence dans les différentes cultures; 2) la spécificité culturelle des outils de dépistage; 3) l'identification de différences dans les facteurs de risque, l'incidence, le début et la prévalence dans différentes cultures; 4) les aspects culturels du processus décisionnel à propos de la prise en charge. Les implications pour la recherche et la pratique sont décrites.

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Dementia is basically a Western diagnostic category and most of the research findings, as well as the instruments used to measure cognitive loss, are from Western sources. However, the phenomenon is thought to be universal. The World Health Organisation has developed a cross-cultural definition :

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain.¹

Currently the research literature provides limited guidance for understanding the cultural aspects of dementia. This paper will critically review current knowledge regarding culture and dementia, outline some of the unanswered questions in the field that may guide future research, and suggest guidelines for practice. "Culture", for the purposes of this review, is defined operationally as a mix of nationality, language spoken, and race. The definition reflects the mixed usage of the term in the literature.

METHOD

The author was requested to review the current medical

literature in order to derive recommendations for health care professionals in primary care with respect to cultural aspects of dementia, including diagnosis and management of dementia across cultural groups. Medline was searched from 1993-97 for key words: mental status, dementia, Alzheimer's, Parkinson's, crossed with culture, cross-cultural comparison, cultural characteristics, ethnic groups, and religion. Eighty-three articles were identified of which 39 that related directly to the subject were reviewed. Additional articles were identified from the reference lists and from experts in the field. Several books on Culture and Mental Health were also reviewed. The literature search was updated in October 2000, with a further 45 articles identified, of which 20 were reviewed.

RESULTS

In general, research evidence available was limited to evidence obtained from comparison between times or places with or without intervention, from opinions of respected authorities, and from small case-control studies, as opposed to randomized controlled trials or well-designed cohort or case-

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control analyses.² Four major areas needing further research with respect to the role of culture in dementia were identified. The first is the recognition of dementia as an entity from culture to culture. Second is the cultural specificity of measures and consequent inaccuracy of diagnosis. The Advisory Panel on Alzheimer's Disease³ called for the development and validation of "screening and diagnostic methods that will work effectively and fairly across ethnocultural variations...". Third is the identification of differences in risk factors, incidence, age of onset, and prevalence across cultures. The final area relates to cultural issues in decision making about management for both demented persons and their caregivers.

A. Does dementia exist in all cultures?

While dementia has been shown to occur across cultures, the experience of dementia in non-Western settings has not been well studied. Moreover, some cultural groups may not even have a word for what we call Alzheimer's disease (AD), quite often using words which mean "crazy" or "mental". Differences in conception of illness have bearing on reporting of symptoms as well as on help-seeking and help-accepting behaviour by those who are dementing, or their caregivers.

Pollitt⁴ presents an anthropological perspective from which he examines the assumption that dementia in old age is a universal phenomenon. He points out the absence of considerations of sociocultural context or the meaning of illness to sufferers and caregivers. He states that there is little knowledge of how the disorders of old age generally are experienced and understood in non-Western settings. He challenges us to consider how positive or negative experiences of old age influence the manifestation and course of dementing disorders. He underlines how the notion of "usefulness" relates to the definition of an individual as intact or decrepit. Other factors are also relevant, such as emotional attachment, supportive family, status, power and influence of the individual.

Pollitt describes research reported by Barker in 1990 on the treatment of the decrepit elderly on the island of Niue in Polynesia, "a rare example of a study of disordered old age in a traditional society".⁴ Barker is described to have found that the elderly who were left unattended or received minimal care were those who demonstrated features of behaviour which match descriptions of dementia. He relates other anthropologic studies of decline in old age in traditional societies.

In summary, studies are needed of the variation between cultures with respect to the definitions of normal aging, mild and marked dementia and the thresholds separating these categories. As Pollitt puts it, "an 'anthropological' awareness of dementia as a social and cultural phenomenon add an important dimension to scientific efforts to understand it in terms of its neuropathology".

B. What approaches to diagnosis can be used across cultures?

For research purposes and in some clinical settings, dementia is diagnosed by means of interviewer-administered questionnaires that estimate cognitive impairment. Screening instruments have established validity and reliability.

However, there is a methodological problem in cross-cultural validation of screening instruments due to difficulty of translation of language and cultural appropriateness of functions

evaluated.^{5,6} Moreover, while it is assumed that interviewers will be able to discover enough about the respondents within a structured interview to allow classification as to functional status, cross-cultural comparative research has demonstrated the impact of the circumstances of the interview. Context may influence both the respondent's capacity and their willingness to respond.⁷

Valid measurement of mental status may be compromised across cultures by the presence of unfamiliar words or culturally inappropriate translations of questions originally written in English, French, or Spanish. One approach to overcoming linguistic, cultural, and situational biases has been to develop batteries of neuropsychologic tasks such as tracing and finger tapping.^{8,9} The second approach that is referred to as "harmonization" develops modifications of the assessment tools which are consistent with the culture and language of the study population.^{10,11} This entails finding appropriate vocabulary and developing equivalent functional status inventories that apply across cultural contexts. It is recognized that inappropriate translation could create artifactual differences between groups if account is not taken of the degree to which translated and changed questions accommodate the culture of the respondent. Ripich et al¹² compared African-Americans and Whites on seven language measures and found no differences but the sample size was too small to draw generalizable conclusions.

Cultural appropriateness of questions assessing cognitive functions and activities is likewise essential. If indices of activities of daily living are perceived as irrelevant or inappropriate, subjects may respond inconsistently.

Kaufert and Shapiro¹³ examined the impact of cultural factors on cognitive evaluation of Native and non-Native elders in the Manitoba Aging Survey. Their study will be described in some detail as it highlights many of the issues in measurement. The survey included questions on ethnicity; level of educational attainment; language most frequently spoken; whether respondents answered the questions themselves, with help, or by proxy; the interviewee's comprehension of the survey questions; and the interviewee's state of mind. The questionnaire was initially printed in English and French. Interpreters translated the questionnaire into more than 15 languages, including Cree, Ojibway, Sioux, and Island Lake Language. The translated versions of the questionnaire in languages other than French, English, Ukrainian, and German were not systematically evaluated through back translation. Kaufert and Shapiro compared scores with independent interviewer-based ratings of attention span and state of mind; level of comprehension; and dependence on proxies. The authors were interested in whether linguistic or cultural biases would increase the prevalence of false positive diagnoses of dementia. Their main intent was to show that standardized instruments cannot be assumed to account for cultural, environmental, and linguistic peculiarities of a population.

Their analysis of the Manitoba Aging Survey revealed large differences between Natives and non-Natives in terms of level of schooling as well as patterns of language. Native languages were used by 83.3% of Native respondents as their principal means of communication, while only 24.4% of the non-Natives relied primarily on a language other than English or French. Dependence on interpreters was, not surprisingly, also markedly

more for Native persons, accounting for three-quarters of the interviews. It is difficult to assess the validity of on-site translation or the degree to which interpreters clarified meaning or prompted correct answers. Interviewers felt that only 48.3% of Natives had satisfactory comprehension, compared to 75.3% of non-Natives.

These differences are related to the large observed differences in summary mental status scores between Natives and non-Natives. For example, only 20% of Natives answered nine or all ten questions correctly in the ten item Mental Status Questionnaire instrument, compared to 77.6% of non-Native respondents. Similarly, 38% of natives scored six or less, compared to 7.3% of non-Natives.

In attempting to explain the summary scores, the authors also conducted individual item analysis which revealed the predicted cultural, situational, and linguistic problems with questions about time, place orientation, and recognition of political leaders. For example, postal addresses have minimal significance for older Native people in remote communities; only 29.7% of Natives knew the Prime Minister, compared to 79.1% of non-Natives; age and birth date questions were confounded by the method of records-keeping in northern Native communities. The authors conclude that there is a need to systematically examine the impact of linguistic, cultural, and structural factors which influence responses of people even when an instrument which has been proven valid and reliable in the dominant culture is used.

Similar findings were obtained by Bohnstedt, Fox, and Kohatsu¹⁴ who studied patients seen at Alzheimer's Disease Diagnostic and Treatment Centres in California to examine possible differences on Mini-Mental Status Examination (MMSE) results for different racial-ethnic groups. White patients had higher scores than Black and Hispanic patients, using the standard 23 cut point on the MMSE. However, there were no differences among groups in the percentages clinically diagnosed as demented. The differences in scores were not accounted for by education, occupation, age, sex, or other variables tested. The authors conclude that MMSE scores underestimate the cognitive capabilities of Black and Hispanic patients. A number of the studies that have been published since 1997 report experience with the MMSE in different populations.¹⁵⁻¹⁷

Teresi et al¹⁸ studied item bias in standard cognitive screening measures in a sample of Afro-American, Hispanic and non-Hispanic White elderly respondents who were part of a dementia case registry study. The psychometric methods of item-response theory were applied to identify biased items. Both cross-cultural and high and low education groups were examined to determine which items were biased. Out of 50 cognitive items examined from six widely-used cognitive screening measures, 16 were identified as biased for either high or low education groups or ethnic/racial group membership. The authors conclude that their analyses are consistent with the findings of others who have used classical item analysis methodology.

Another approach to confounded measurement is Mungas and colleagues¹⁹ who have developed a statistical correction for effects of age and education on the Mini-Mental Status measure. They have tested the efficacy of the MMSAdj as a screening test for dementia, concluding that the adjusted scores appeared to

correct for the influence of ethnicity and language of test, when compared to the raw scores. There was greater stability of sensitivity and specificity across educational levels and ethnic groups in a study of almost 3,000 Whites, Hispanics, and Blacks in the United States.

A cognitive screening instrument designed specifically for application in cross-cultural epidemiological studies of dementia was reported in 1993 by Glosser et al.²⁰ The Cross Cultural Cognitive Examination was validated in Guam in a sample of randomly selected subjects, both healthy and demented; a sample of healthy subjects in the United States mainland; and three groups of patients with neurological disorders (AD, Parkinson's disease with dementia and Parkinson's disease without dementia) in the US mainland. This instrument appears to be a brief and reliable screening device that is "culture-fair". Another promising research measure is the Community Screening Interview for Dementia, developed as a cross-cultural screening instrument for dementia.²¹ The development of the scale involved harmonization, translation, back translation, and pilot testing for use in five sites. Cognitive scores are supplemented by informant scores, producing better sensitivity and specificity. However, such measures have little clinical utility. An example of a clinical cognitive testing instrument is the Cambridge Cognitive Examination, described as the 'second most popular cognitive testing instrument in use by Israeli clinicians'.²² A small case-control study of a Hebrew version revealed moderate sensitivity, excellent sensitivity, and a strong predictive value (83.6%).

In summary, while there has been progress made in harmonization of measures across cultures, analysis of the results of research studies remains confounded by the different diagnostic criteria and measures used by different authors. Clinical application of standardized measures remains limited.

C. What are the genetic and environmental risk factors across ethnic groups?

Research findings are conflicting as to true cross-cultural differences in incidence and age of onset but there do appear to be real differences that are not related to measurement artifact. While overall dementia rates seem to be generally similar among nations, relative frequencies of the two major subtypes, AD and vascular dementia vary. Alzheimer's disease is the major subtype in most Western nations. In contrast, vascular dementia has been reported to be the dominant subtype in Japan and possibly other Asian nations,^{23,24} recognizing the lack of standardization in case finding and classification in studies. A 1994 Korean study²⁵ reports similar prevalence of dementia to Western countries, with greater prevalence of Alzheimer's than vascular type. They also identify alcohol as a cause of dementia in their elderly population, perhaps related to the high prevalence of alcoholism in Korea or to a high susceptibility of Korean alcoholics to the development of dementia. Research is needed across populations as to the potential interaction of risk factors with age of onset, which will utilize harmonized diagnostic approaches and will link clinical findings with autopsy results where possible.

Genetic factors have some relationship to onset. Autosomal dominant mutations at three different genetic loci have been shown to be associated with onset of dementias of the Alzheimer type (DATs) that typically develop between the fifth and seventh

decade. These mutations are rare. As of 1996, there were only 20 known families with mutations in the beta-amyloid precursor gene on chromosome 21, only a few families with the "presenilin-2" gene on chromosome 1, and fewer than 100 known families with the "presenilin-1" gene on chromosome 14.²⁶ It has been found that the apolipoprotein E gene (APOE) contributes to late onset AD.²⁷ In a 1996 study of AD,²⁸ it appeared that APOE genotype did not vary significantly across ethnic groups nor did the frequency of positive family history in first-degree relatives. In fact, the prevalence of most risk factors was remarkably similar across ethnic groups. However, the authors point out that family history is difficult to quantify as it depends on family size and longevity. They give the example of the lack of family history for Jews who lost older relatives in the Holocaust.

In contrast, a study was carried out of APOE among the Amish²⁹ because of a significantly lower prevalence of dementia when compared with other populations of similar age.³⁰⁻³² Pericak-Vance and colleagues²⁹ studied a large inbred family with six late onset family members. They suggest that the lower frequency of dementia among the Amish is related to the decreased frequency of the APOE-4 allele, with additional genetic factors at play in the family cluster. Related work has suggested a protective effect for the epsilon 2 allele.³³

The relative importance of genetics and environment in incidence and prevalence of dementia has been studied longitudinally in the Honolulu-Asia Aging Study.^{34,35} White and colleagues³⁴ studied whether the prevalence of DAT differs between Japanese issei (first generation) and nisei (second generation) who have migrated to the island of Oahu. The major conclusion of their study is that when Japanese men (women were not studied) migrate to Hawaii, they appear to be more susceptible to the development of DAT. An accompanying editorial³⁶ suggests several cautions. First, there could be genetic founder effects such that the migrating population was a genetically biased sample of the parental population. Theoretically, it is possible that the migrants might have had relatively higher frequencies of the APOE epsilon 4 allele. Second, question is raised as to the validity of the clinical criteria, both for DAT and for vascular dementia which is their comparison group. Data from autopsies on the cohort in White et al³⁴ may provide important evidence regarding their conclusions. Third, the editorialists question the comparability of methods used to determine prevalence in Japan. While the diagnostic measures used by White et al have also been applied in most of the recent incidence and prevalence studies in Japan, there may be differences in sampling as well as potential differences in sensitivity, specificity, and predictive value of the screening instruments both between and within studies. Fourth, it may not be possible to distinguish the predominant cause of the dementia when both DAT and vascular dementia exist in the same individual. Finally, they raise the differential survival rates among subjects with DAT and vascular dementia as possibly influencing prevalence estimates. In common with Hendrie et al,³⁷ they point out the advantages of incidence studies in making etiologic inferences. Nevertheless, the Hawaiian data should encourage further studies in migrant populations and cultures.

Hendrie's group used a harmonized instrument developed in Manitoba¹³ to study two Black populations for prevalence of

dementia and AD, one in West Africa and one group in Indianapolis who derive from slaves imported from West Africa. They describe their study as the first to report significant differences in rates of dementia and AD in two different communities with similar ethnic origins. Age-adjusted prevalence rates of 2.29% for dementia and 1.41% for AD in Ibadan, Nigeria compare to 4.82% for dementia and 3.69% for AD in an Indianapolis community sample. While differences in lifestyle were taken into account in the survey, the authors point out the need for incidence studies which can observe changes within subjects.

The study by Perkins et al³⁸ is an example of small studies found in the literature which compare population subgroups in a particular geographic location. They studied incidence and prevalence of dementia in a multiethnic cohort of municipal retirees in Houston, Texas. They were able to study a cohort of 755 retirees, with 20 retirees diagnosed as having dementia over an 11 year period (1980-91). They derived age-adjusted and sex-adjusted rates, concluding that the risk of dementia was more pronounced for Hispanic and Black men compared with White men. However, the sample size is acknowledged by the authors as small. Moreover, Bohnstedt's findings¹⁴ of the influence of race-ethnicity on MMSE scores may apply here as well.

In summary, additional longitudinal studies in different population groups are needed to clarify the role of genetics and environment in the etiology of dementia as well as the relative incidence of subtypes. Alcohol should not be forgotten as a potential cause of dementia. At the same time, further work is needed to elucidate the genetics of AD. Autopsy studies are important to confirm or deny the accuracy of clinical diagnoses according to existing criteria.

D. Are decisions about management affected by cultural differences?

Decisions about management are likewise complicated by cultural differences in the populations under consideration. In a 1994 paper by Valle,³⁹ a culture-fair behavioural assessment and intervention model is presented as a framework for research and practice. The model was subjected to an empirical test in a study of Latino and Anglo caregivers of dementia-affected elders in San Diego. The study demonstrated ethnic group differences along four dimensions: reactivity to caregiving burden, caregivers' health status, coping and helpseeking styles, and configuration of social support received from social network members. These differences persisted after correction for income, education and mean age, and have implications for intervention.

A 1996 study⁴⁰ examined Australian-born and ethnic aged persons in Queensland, with respect to use of services and residential care prior to and after assessment, and with respect to functional, medical, and psychosocial factors. The group with non-English speaking background was most likely to be both younger and under referred. When they were referred, they were more likely to be recommended for nursing home placement, a likely reflection of more advanced disease at time of referral.

A study of the illness narratives of ten caregivers of African-American elders with dementia⁴¹ suggested that reports of 'lesser burden', compared with White caregivers, may not accurately reflect their experience. Meanings and interpretations must be

considered in relation to social and political context, such as segregation, racism, and economic exploitation. The narrative approach was also used in a study of family caregivers from African-American, Chinese-American, Irish-American, and Latino backgrounds to show the relation between cultural factors and the stories of illness.⁴²

Auger⁴³ points out that the multicultural elderly may be invisible, with consumer needs being met by family and friends. She also asserts that services are not available in the language of the minority group nor are they based on cultural expectations and values. As a consequence, their needs may not be met. She states, "... 'we' ask 'them' what they need from 'our' system of health care delivery rather than facilitating their own expression of their needs."

Connell and Gibson⁴⁴ published a review and analysis of the empirical literature from 1985 that has examined the impact of racial, ethnic, and cultural differences in dementia caregiving. Compared to White caregivers, non-White caregivers were less likely to be a spouse and more likely to be an adult child, friend or other family member; reported lower levels of caregiver stress, burden and depression; endorsed more strongly held beliefs about filial support; and were more likely to use prayer, faith, or religion as coping mechanisms.

DISCUSSION

Implications for research

In all four of the areas considered in this paper, there are implications for future research. 1. More qualitative studies are needed of dementia across cultures. 2. Standardization of diagnostic approaches, including measures that have been adjusted for particular cultural groups, is essential for research. Some measures will have clinical application. 3. In summary, additional longitudinal studies in different population groups are needed to clarify the role of genetics and environment in the etiology of dementia as well as the relative incidence of subtypes. Long time misuse of alcoholic beverages should not be forgotten as a potential cause of dementia-like symptoms. At the same time, further work is needed to elucidate the genetics of AD. Autopsy studies are important to confirm or deny the accuracy of clinical diagnoses. 4. Culture-fair approaches need to be developed and evaluated for service delivery to both those diagnosed with dementia and their caregivers.

Implications for practice

Practitioners need to be sensitive to the cross-cultural aspects of dementia. It is essential to question patients and their families about the meaning of aging and about their experience and understanding of symptoms which, in Western terms, signify dementia. Proactive questioning is important in that patients and caregivers may not identify their experience as "disease" or may not know that assistance is available.

Screening with the MMSE may result in over-diagnosis of dementia, in those individuals with minority languages, less education, or in isolated communities. Yet it remains the most readily available instrument for clinical screening. Whenever possible, individuals from ethnic communities who are screened as dementing by the MMSE should be reviewed by someone with knowledge and experience of aging in that culture.

Knowledge of family history, family structure and social context is essential to rational and compassionate management of those identified as dementing. Those providing longitudinal care for families are in a position to track familial incidence that may be related to genetics or environment, and to provide appropriate intervention. While prevention is not yet possible, except for dementia-like symptoms associated with alcohol, early intervention can minimize the social costs to affected individuals and their families.

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