

Literature Review

Dementia and Cultural Considerations

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According to the Canadian Alzheimer Society (2006), an estimated 435,000 Canadians over 65 years of age have Alzheimer Disease and related dementias. By 2011, additional new cases of dementia are expected to reach 111,560 per year. By 2031, over 75 million Canadians are expected to have Alzheimer Disease and related dementias. As life expectancy in Canada continues to increase, the prevalence of dementia rises accordingly. Additionally, societal mobility and immigration continue to increase, as does the potential for increased cultural and linguistic diversity (Feser & Bernard, 2003). Surprisingly, limited research has been conducted on the mental health of ethnic minority elders (Ilfie & Manthorpe, 2004). Previous studies have isolated mental healthcare and ethnicity, however, research has shown that ethnic factors can indeed be specific to dementia (Morrow-Howell, Chadiha, Proctor, Hourd-Bryant & Dore, 1996). Therefore, there is an unprecedented need for Canadian healthcare providers to respond to an increasing population of dementia sufferers, families, and caregivers in a culturally competent way – considering both the disease and contextual cultural factors.

According to Torti, Gwyther, Reed, Friedman & Schulman (2004), “[d]ementia is a complex clinical syndrome with many etiologies” (p. 99). The most common form of dementia is Alzheimer disease (AD), a progressive neurodegenerative disease whose etiology is poorly understood. AD represents 50% to 90% of dementia occurrences, depending on the population studied. Vascular dementia, another common form, comprises the majority of non-Alzheimer cases. While the medical model generally considers dementia a degenerative brain disease originating from damage to the neurons, others suggest the degeneration may also result from external factors, including those related to culture (Innes, 2003; Ilfie & Manthorpe, 2004).

Additionally, Manly and Mayeux (as cited in Anderson, Bulatao & Cohen, 2004) report causal factors of dementia have also been attributed to Apolipoprotein E (APOE). It is significant to note that APOE varies in prevalence between ethnic groups (Henderson & Henderson, 2002). Differences in the frequency of the APOE e4 allele create opportunities to investigate the independent effects of genetics and environment on the development of AD. However, most APOE allele carriers do not develop dementia, and about one half of Alzheimer’s disease is not associated with the APOE epsilon 4 allele. Non-genetic risk factors of AD include stroke, hypertension, diabetes, myocardial infarction and coronary disease, head injury, exposure to possible protective factors and cognitive reserve (Manly & Mayeux, 2004, p.117). Clearly, further research is required in the relationship between ethnicity and the diagnosis of dementia.

Cultural factors alone may play an important role in the prevalence of dementia. In a comparison study between Japanese and Japanese-Americans, there was a significantly lower rate of dementia among the Japanese in Japan versus Japanese-Americans (Ilfie & Manthorpe, 2004). Therefore, migration factors influencing the syndrome profile of dementia are also worthy of further investigation.

Moreover, cultural perspectives in defining dementia are of critical importance in diagnosis. As Henderson and Henderson (2002) clearly state, “[t]he cultural constructions of health and illness may be viewed as a device for categorizing or systematizing symptoms. Illness constructs reflect core cultural values in that they express normative understanding about the nature and causes of anomaly and dysfunction” (pp. 198-199). Simply understanding cultural norms, values, beliefs, and frameworks of disease would greatly benefit and aid healthcare providers working with various ethnic groups with dementia (Dilworth-Anderson & Gibson, 2002, p. S56).

Without a cultural context, the diagnosis of dementia is an enormous challenge. A major obstacle resides in the assessment tools used for diagnosis (Torti, Gwyther, Reed, Friedman & Schulman, 2004). The majority of diagnostic tests are based on cognitive assessments not validated within various cultural contexts (Iliffe & Manthorpe, 2004). Artero, Tierney, Touchon and Ritchie (2003) state that “the absence of specific biomarkers for AD diagnosis must be based on biological and behavioral indicators which overlap with changes observed in normal elderly” (p. 390). Attempting to apply cognitive assessment tools to variant levels of educational, cultural and linguistic understandings are inadequate and irrational (Hall, Gao, Emsley, Ogunniyi, Morgan & Hendrie, 2000).

Feser and Bernard (2003) further emphasize the need of cultural competence in healthcare that “encompasses a set of values, behaviors, attitudes, knowledge, and skills which allow providers to offer client care which is respectful and inclusive of diverse cultural backgrounds. These include developing good interpersonal relationships central to interpersonal and cross-cultural practice, and understanding that culture is context” (p. 135). Furthermore, respecting a person’s culture, beliefs and individuality is often identified as integral to competence and sensitivity among healthcare providers, but also as an indicator of quality service.

Conversely, The National Institute for Mental Health (England, 2003) cautions that special cultural sensitive services may send mixed messages through marginalizing minority ethnic communities further by suggesting to health providers that ethnicity is a fringe rather than a mainstream issue. The benefits of integrating, rather than separating, dementia care based on person-centered care approaches may be to eliminate unlawful discrimination, promote equality, and foster good race relations. The key to promoting a system that emphasizes an integrated approach, ethnic monitoring, and a quality assurance system is to focus on the service user’s experience (Iliffe & Manthorpe, 2004).

When addressing culture as a contextual factor, it is important to remember that country of birth is a poor and inadequate indicator of ethnicity (Trauer, 1995). Culture exerts its effects on individual beliefs and behavior internally, despite the fact it is learned externally through interaction with others (Dilworth-Anderson & Gibson, 2002). Nyatanga (2002) and Iliffe and Manthorpe (2004) further emphasize this difference between intra-culture and inter-culture saying there may be some aspects of cultural dissonance, where an individual deviates from the known cultural norm, changing the behaviour according to the acculturation process. Moreover, “[I]ack of attention to intra-ethnic variability may have unfortunate consequences, including the promotion of stereotypical thinking among service providers and researchers, less accuracy in identifying high-risk sub groups of minority elderly for interventions, and less well-developed etiological models” (Hinton, 2002, p. S51).

Cultural norms play a significant role in the administration of responsibilities and expectations of caregivers. According to Kosloski, Schaefer, Allwardt, Montgomery and Karner (no year) and Neufeld, Harrison, Stewart, Hughes and Spitzer (2002), family involvement and responsibility translate into different perceptions of need for services; therefore, these beliefs will also influence and impact the use of a supportive service by caregivers of dementia patients. With respect to the relationship of the caregiver to the patient, there appear to be clear differences in normative expectations toward care of the elderly that are associated with different familial roles. According to Innes (2003), women are most likely to be the primary caregivers. These women tend to be among the lower-paid sector of the economy, have additional domestic responsibilities and dependents, and have few formal qualifications. As Cagney and Agree (1999) divulge, approximately 70-80% of the care of non-institutionalized frail older persons is provided by family members, friends, and other informal supports, with or without supplementary assistance from formal services such as home health. Therefore, healthcare providers need to be educated in dealing with not only a client, but also with associated family members and caregivers within a culturally cognizant framework.

There are several barriers to providing proper care to ethnically diverse dementia patients. The communication barrier is perhaps most notable as it manifests in various forms. For instance, the South Asian culture simply has no name for dementia (Iliffe & Manthorpe, 2004). And, behavioral changes, such as grabbing food from someone's plate at the table, are classed as 'childish' and are consistent with cultural models of expected old age behaviour (Henderson & Henderson, 2002; Teng, 2002). Therefore, to convey the diagnosis of dementia becomes a great challenge – especially for healthcare providers unaware of this difference in perception.

Distinguishing between language miscommunications and dementia is also important. While dementia patients lose the ability to communicate in their acquired language, it might not be as significant as the fact that speech problems are exacerbated by dementia. Therefore, cultural sensitivity needs to extend to nonverbal methods of communication to ensure accuracy of the interpretation, or inferences made, of the observed behaviour (Iliffe & Manthorpe, 2004; Nyatanga, 2002).

Lastly, a most unfortunate result of communication barriers is the inability to accurately communicate informed consent (Kaufert, 1999). In many cases, a family translator chooses not to disclose the extent of the diagnosis to the patient as cultural values discourage full disclosure of the severity of the disease. In other cases, language itself is an obstacle – resulting in unclear and incomplete understandings of what is at risk. Furthermore, as Seale and Van der Geest (2004) explain, “the meaning of suffering is very different in an ‘anesthetic’ culture where medical remedies are widely resorted to, if compared with a religion society in which human suffering may have positive moral significance.” To assume the western model of intervention is desired by people of all races and ethnic backgrounds would be ignorant and erroneous.

There are several blindspots in the research that has thus far been conducted. A significant factor has been failure of randomization. As Nazroo (2004) states, “standardization is effectively an attempt to deal with the non-random nature of samples used in cross-sectional studies – controlling for all relevant ‘extraneous’ explanatory factors introduces the appearance of randomization” (p. 695). However, an attempt to introduce randomization into cross-sectional studies by adding controls has not been made. Iliffe and Manthorpe (2004) further comment that cross-cultural studies are helpful because they caution against a simplistic view of the ways in which ethnicity might influence an individual's vulnerability to, and experience of, dementia; revealing a problem of great relevance, that of “category fallacies” (p. 288). Areas needing attention and consideration in future research include: lack of control groups; lack of both qualitative and quantitative research; the introduction and use of culturally sensitive tools validated to ethnic groups; generalizations of analysis in sub group minorities (stereotypes/generalizations); and reconsideration of socioeconomic variables as confounders.

The need for greater, deeper, and more accurate research is critical. Populations lacking research and consideration include the French, Muslim, and indigenous people. The lack of readily available research in English for the French community is a gross oversight to healthcare providers in Canada, specifically those in western provinces. Additionally, very little research on dementia and dementia caregivers has been done among indigenous populations of North America (Henderson & Henderson, 2002; Jervis & Manson, 2002). The Chinese community has been given the most attention in studies, and can therefore provide clues and areas needed for further research.

As life expectancy continues to increase, the prevalence of dementia grows accordingly. Overall, very little research exists, yet the need and demand for culturally cognizant information in dementia diagnosis and care continues to increase. It is vital the healthcare community of Canada take action and respond accordingly with sensitivity, competence, and knowledge.

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