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Feasibility and Validity of Dementia Assessment by Trained Community Health Workers Based on Clinical Dementia Rating

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Abstract

Background/Objectives—Ethnic minority elders, particularly recent Asian immigrants, have a heightened prevalence of dementia but lack timely diagnosis and treatment. This study was designed to determine the level of agreement between dementia rating by trained community health workers (CHWs) based on the Clinical Dementia Rating (CDR) and the gold standard, physician diagnosis.

Design—Cross-sectional validation study.

Settings—Key community gathering places such as ethnic churches, senior centers, low-income elderly apartments, and ethnic groceries in the Baltimore-Washington metropolitan area.

Participants—Ninety community-dwelling Korean American elderly (aged 60 years or older).

Measurements—The CDR is a standardized clinical dementia staging instrument to assess a patient's cognitive and functional performance after a semi-structured interview protocol. A total of six CHWs who were trained and certified as CDR raters interviewed and rated study participants. A bilingual geriatric psychiatrist evaluated the participants independently for dementia status.

Results—61.1% of the participants were rated as having either mild cognitive impairment (CDR=0.5) or dementia (CDR=1 or higher) by CHWs, as compared to 56.7% diagnosed by the clinician. A receiver operating characteristic (ROC) curve analysis demonstrated a good predictive capability for CDR rating by trained CHWs (ROC area under the curve=0.86 [95% confidence interval=0.78–0.93], with sensitivity=85.5% and specificity=88.6%) in detecting mild cognitive impairment and dementia.

Conclusion—The findings provide preliminary evidence that trained CHWs can effectively identify community-dwelling Korean elderly with mild cognitive impairment and dementia for early follow-up assessment and care in the resource scarce community.

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Keywords

dementia; Clinical Dementia Rating; community health worker; Korean; elders

INTRODUCTION

As the average life span in the U.S. increases, the size of the elderly population aged 65 or older is expected to increase from 35 million in 2000 to 71 million by 2030.¹ The percentage of ethnic minority elders is expected to increase at a much higher rate than that of Caucasian elders. Projections indicate that from 2000 to 2050, the older Caucasian population will double, and the number of African American elderly will quadruple. During this same period, the Asian and Hispanic elderly populations will both increase to seven times their current numbers.²

One of the most pressing public health issues associated with the increase in minority elderly population is dementia care. The current prevalence of dementia is 6–13% among the general U.S. population, as compared to 10–25% in the ethnic minority elderly.^{1,3} Since many of the minority elders are foreign born, challenges of dementia diagnosis and delivery of dementia-related social services are further compounded by language barriers. Even when language is not an immediate barrier, numerous cultural barriers still prevail in provision of dementia-related services for minority elderly.

Korean Americans (KAs) constitute one of the most homogeneous Asian subgroups in terms of race, language, and culture, representing the fourth largest Asian American subgroup.⁴ Given their recent immigration history, KA elders are predominantly monolingual, first-generation immigrants who maintain strong traditional expectations of family support.⁵ As in other ethnic communities, the increasing number of older KA population is poised to impose significant care demands, yet little attention has been paid to the dementia care in this one of the fastest-growing Asian subpopulation. The few available studies of KAs^{6–8} have revealed that KA immigrants lack basic knowledge about the diagnosis, treatment, and cause of dementia, resulting in a lack of follow-up treatment and care. Often, they treat dementia as part of the normal aging process and interpret it as insanity, leaving the affected elder undiagnosed and untreated and their family feelings of shame and stigma.

One of the important steps in addressing the unmet needs regarding dementia in this population is to build the capacity to adequately screen people with dementia for necessary follow-up assessment and care. Community health workers (CHWs) are front-line outreach paraprofessionals who have emerged in response to the need for effective risk reduction interventions that are more accessible to underserved populations with limited resources, such as culturally and linguistically isolated recent immigrants.⁹ However, use of CHWs to improve mental health of community has been rarely attempted. One study in England has revealed that the integration of a CHW (called a “link” worker) into a community center resulted in more referrals for psychiatric services in the Pakistani community.¹⁰ Similarly, studies using CHWs in India^{11,12} and Brazil¹³ resulted in early detection of dementia in the community, though low sensitivity (3.8%) was of concern.¹² As far as we know, no previous study has investigated the use of CHWs for dementia screening and care in minority community in the U.S.

Guided by the principles of community-based participatory research,¹⁴ KA community in the greater Baltimore-Washington metropolitan area has formed an academic institution-community partnership to train bilingual CHWs as a sustainable community workforce to conduct dementia screening and referral for follow-up care. Dementia assessment based on

neuropsychological tests (e.g., Mini Mental State Exam) is very much affected by education, age, language, or cultural background;^{15,16} hence, its' utility may be limited for certain ethnic minority groups such as KAs who are predominantly monolingual. In contrast, the Clinical Dementia Rating (CDR) is a clinical dementia staging instrument administered by a physician or a trained non-physician health professional who assesses a patient's cognitive and functional performance.¹⁷ However, the availability of bilingual physicians or non-physician professionals is scarce in minority community. Thus, the purpose of this study was to examine whether CDR conducted by trained lay CHWs without previous clinical experience could achieve an acceptable level of agreement with the gold standard, physician diagnosis. To our knowledge, this is the first study to look at the feasibility and efficacy of dementia screening by trained CHWs in the U.S.

METHODS

The Sample

Study procedures were approved by the Johns Hopkins Medical Institute Institutional Review Board. Participants of this study were from the Memory and Aging Study among Korean in Maryland (MASK-MD), an epidemiologic study of prevalence of dementia in a community-representative sample of Korean elders (60+ years) in the Greater Baltimore-Washington area. The recruitment of MASK-MD was done in two stages. The first stage dovetailed the Health Literacy Study for Hypertension sponsored by the NHLBI that screened Korean elderly for dementia in 20 ethnic churches selected based on denomination, size, and regional distribution out of 150 Korean churches in the region. The second stage consisted of dementia screening at the local Korean senior centers, low-income elderly apartments, and ethnic groceries. Altogether, 1,118 KA elders (mean age=70.5±7.0 years; female=67.1%) completed a Korean version of the Mini-Mental State Examination (MMSE-KC).¹⁸ The MMSE-KC has been repeatedly validated, and cutoff scores by age, gender, and education have been established for Korean elders.^{18,19}

Of 1,118 KA elders, 186 (mean age=75.3±.6 years; female=78.0%; MMSE-KC score 20=50.0%) were invited to participate in the follow-up phase of detailed cognitive assessment at a community center located in a suburban area. Of 186, 118 or 63.4% agreed to participate and completed the follow-up cognitive assessment. Each participant except for one was accompanied by a family member or a caregiver who provided collateral information to facilitate the dementia evaluation, resulting in 117 with CDR scores available. Of 117, physician assessments were done for 90 because of time and scheduling constraints, resulting in 90 in the final sample.

Training of CHWs

In collaboration with our community partners, six CHWs were identified via ethnic media advertisement and word-of-mouth. They were predominantly female (n=5), had a college degree and were bilingual. Training protocol of CHW consisted of three components: web-based CDR training, group training, and physician validation. First, CHWs completed standardized web-based self-training modules for CDR operated by the Alzheimer's Disease Research Center at Washington University in St. Louis (<http://alzheimer.wustl.edu/cdr/TrainingA/Overview.htm>). It took 8–9 hours for each CHW to complete the three training modules and six test modules. Once CHWs successfully completed the on-line modules, they received 4-hour structured group training by a psychiatrist to further develop their skills and increase confidence in administering the CDR. Upon completion of both on-line and group training, CHWs interviewed participants under observation by a bilingual psychiatrist. At least two CDR interviews conducted by each CHW were observed. In addition, peer CHWs who had already completed all training conducted CDR interviews concurrently with

the CHWs in training in order to ensure the compatibility of the CDR rating. After close observation and cross-evaluation by both the psychiatrist and peer CHWs, trained CHWs conducted CDR interviews independently.

Clinical Dementia Rating by CHWs

The CDR scale evaluates the severity of dementia and includes six cognitive-functional domains: Memory, Orientation, Judgment and Problem-solving, Community Affairs, Home and Hobbies, and Personal Care.¹⁷ Semi-structured interview data from the patient and caregiver are reviewed to determine the functional impairment ratings in each cognitive category. These category scores (or “box scores”) are then analyzed using special scoring rules to determine a global CDR score on a 5-point scale (0–3), with 0 being no cognitive impairment, 0.5 as having mild cognitive impairment (MCI), and a score of 1 or greater as having clear signs of dementia. The CDR has been mainly utilized by physicians, although one study has revealed that agreement of the diagnosis of dementia with the use of CDR is high between physicians and nurses.²⁰ The CDR has been translated and validated in Korean.¹⁶ A study conducted in Korea reported a high inter-rater reliability (Kappa=0.86–1.00) among three neurologists and one psychologist.²¹ Using CDR, a trained CHW interviewed the participant and the caregiver; this process took about 20 to 40 minutes to complete.

Physician assessment

Each participant was evaluated separately by a geriatric psychiatrist who was blind to the CDR score. The physician assessment consisted of a full neuropsychiatric assessment that included neurological examination, depression module of the Structured Clinical Interview for DSM Disorders, and Korean version of Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) neuropsychological battery.¹⁸ An accompanying family member or caregiver provided collateral information on the participant’s general function based on the Lawton Instrumental Activities of Daily Living (IADL) Scale. The psychiatrist then diagnosed dementia according to the criteria of the DSM-IV.²²

Analysis

We summarized sample characteristics using descriptive statistics. Spearman’s rank correlation tests were employed to evaluate concurrent validity for the MMSE-KC and CDR with physician diagnosis. The MMSE-KC was coded as normal cognitive function versus probable dementia based on age, gender, and educational-adjusted cut-off score for Korean elders, whereas both the CDR and physician ratings were classified into the following categories: normal, MCI, and dementia. To assess whether CHWs detected dementia correctly, as compared to expert clinician diagnosis (gold standard), sensitivity and specificity tests were performed by compiling a receiver operating characteristic (ROC) curve and examining the area under the curve. The ROC area under the curve ranges from 0.50 to 1, with higher values indicating greater accuracy of an assessment tool.²³

RESULTS

Sample characteristics

The mean age of the sample was 75.7 (SD=7.8) years. The majority (77.8%) were female and 64.4% had not completed high school. At least two out of five (43.3%) reported living alone. On average, participants had lived in the U.S. for about 24 years (mean=24.4, SD=9.9). Most had some form of health insurance. Sixty percent had two or more comorbid diagnoses; hypertension was the most frequent diagnosis (72.2%), followed by diabetes (28.9%), with a mean number of prescription medication of 3.1 (SD=1.9). Scores on the

MMSE-KC and CDR (sum of boxes) ranged from 3 to 30 (mean=20.9, SD=5.7) and 0 to 17 (mean=2.6, SD=3.8), respectively (Table 1).

Dementia classifications

Using three different approaches, about 22–29% of the sample was classified as having dementia (Table 2). MMSE-KC yielded a higher rate of dementia than did the other two approaches. CDR ratings by CHWs resulted in more cases of MCI (38.9% vs. 30.0%) and fewer cases of normal cognitive function (38.9% vs. 43.3%), as compared to physician diagnosis. The correlation between the CDR and physician ratings was strong (Spearman's $\rho=0.80$, $p<.001$). The correlation between the MMSE-KC and physician ratings was statistically significant but low (Spearman's $\rho=0.37$, $p<.001$).

Prediction of dementia

ROC analysis revealed good predictive capabilities of CDR performed by CHWs (Figure 1). Specifically, ROC analysis resulted in an ROC area under the curve of 0.86 (95% confidence interval =0.78–0.93), with an 85.5% sensitivity and 88.6% specificity in detecting KA elders with cognitive impairment (i.e., MCI and dementia).

DISCUSSION

Our findings indicate that CHWs can be trained to build community capacity for early detection of dementia in resource poor communities. Often, identifying and using a proficient group of bilingual clinicians committed to examining and improving dementia care among elders in linguistically and/or socially-isolated ethnic minority communities (e.g., Korean) presents a significant feasibility challenge. Using trained CHWs as first-line screeners for probable dementia appears to be not only a practical but also a sustainable approach in resource-poor communities with a substantial number of recent immigrants (e.g., Hispanic, Asian American). Future research is warranted to determine the validity of CHWs' assessment of dementia in a larger sample, as compared to expert clinician diagnosis and other established criterion (e.g., biological markers).

The KA sample had higher rates of MCI and dementia (30.0% and 26.7%, respectively) than the current prevalence of MCI (16% to 27%)^{24–26} and dementia (10% to 25%) among ethnic minority elderly in epidemiological studies.^{1,3} This degree of discrepancy may have to do with our oversampling of elders who scored less than the adjusted cut-off points on the MMSE-KC; given that the goal of the study was to compare dementia ratings by CHWs to physician diagnosis to establish compatibility between the two, we aimed to include about half of our study sample with low MMSE-KC scores (<20) and ensure enough cases for probable dementia.

The MMSE is the most commonly used screening instrument for cognitive impairment, including dementia, across different ethnic groups. Yet, the correlation between MMSE-KC and physician ratings was low in our sample. A recent meta-analysis²⁷ revealed that diagnostic validity of the MMSE was no better than shorter, alternative tests in community studies and tended to be inferior in specialist settings (i.e., memory clinics). First-line screening by newer instruments with higher sensitivity and diagnostic accuracy (e.g., Montreal Cognitive Assessment or Mini-Cog)^{27,28} appears to be a better approach to identifying people “at risk” before following them up with more detailed measures such as the CDR.

While available studies indicate that healthy older adults are generally receptive of screening for dementia,²⁹ it is unclear whether this attitude holds true in a culture in which dementia is often associated with feelings of stigma, such as Korean society.⁶ In our study, the response

rate (i.e., those who accepted a CDR interview) was high (63.4%). In a mailed survey of healthy members of retirement communities in North Carolina (ethnicity unknown, 68% women), 49% expressed an interest in routine screening for memory problems.³⁰ In another study of a geriatrics clinic population (67% African American, 72% women),²⁹ 74% said “definitely yes” to having a test for memory if a relative suggested it, and 55% wanted a memory test as part of the usual medical examination, and noted that cognitive testing is reassuring, not anxiety-provoking. Future research is warranted to identify correlates of intention for early dementia screening in elders with diverse cultural backgrounds.

The study limitations should be mentioned: First, the trained CHWs had at least a college level of education, which may be a reflection of a higher level of educational attainment of Asian Americans compared to the general population (52% vs. 30% college degree holders). In addition, the sample may have included those who had more subjective complaints of memory loss and poor health, which might have contributed to the higher rate of dementia. Finally, our goal was not to establish prevalence rates of dementia in the KA population but to validate CHW dementia ratings against physician diagnosis. As indicated earlier, we oversampled those who scored low on the MMSE-KC (<20) in order to recruit sufficient numbers of “cases” for probable dementia. This, in turn, might have resulted in high rates of dementia as compared to those in population-based studies.

CONCLUSION

With the rapid increase in the aging Asian population, significant disparities in healthcare have emerged, especially those related to late-life mental disorders such as dementia. KAs, in particular, are facing an unprecedented challenge but lack important practical knowledge in addressing this emerging public health concern. Early detection of dementia is a critical first step in addressing the issue in this resource-poor new immigrant community. Our findings provide preliminary yet promising evidence to suggest an effective and realistic strategy for early detection of dementia using trained CHWs in the resource-scarce community.

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Figure 1.
Receiver operating characteristic (ROC) curve analysis

Table 1

Sample characteristics (N=90)

Variable	n (%)	Mean (SD)
Age, yrs (range 63–92)		75.7 (7.8)
Gender		
Male	20 (22.2%)	
Female	70 (77.8%)	
Living arrangement		
Living alone	39 (43.3%)	
Living with others	51 (56.7%)	
Education		
Less than high school	58 (64.4%)	
High school graduate	17 (18.9%)	
Some college or more	15 (16.7%)	
Years in the US, yrs (range 3–41)		24.4 (9.9)
Insured		
Medicare	76 (84.4%)	
Medicaid	56 (62.2%)	
Medicare/Medicaid	55 (61.1%)	
Other	9 (10.0%)	
Co-morbidity	54 (60.0%)	
Number of prescribed medication (range 1–11)		3.1 (1.9)
MMSE-KC (range 3–30)		20.9 (5.7)
CDR sum of boxes (range 0–17)		2.6 (3.8)

Table 2

Dementia classifications according to three approaches

Stage	CDR n (%)	MMSE-KC ^a n (%)	Physician diagnosis n (%)
Normal	35 (38.9)	64 (71.1)	39 (43.3)
MCI	35 (38.9)	--	27 (30.0)
Dementia	20 (22.2)	26 (28.9)	24 (26.7)

^aMMSE-KC does not have a category for mild cognitive impairment (MCI).