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# Videoconference Diagnosis and Management of Choctaw Indian Dementia Patients

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## Abstract

**Background—**To report a 5-year experience using videoconference (VC) technology to diagnose and treat adult members of the Choctaw Nation with symptoms or complaints of cognitive impairment.

**Methods—**Patients were given the option of VC or face-to-face clinic. Prior to their VC session, patients underwent neuropsychological testing, Clinical Dementia Rating, Geriatric Depression Scale and Neuropsychiatric Inventory, brain CT, and routine blood tests.

Physical observations made by VC included eyesight, hearing, facial expression, gait and station, coordination, tremor, rapid alternating movements, psychomotor activity, and motor tests of executive function. Cogwheeling and rigidity were tested by our on-site nurse, who also obtains vital signs as indicated.

**Results—**From January 2005 to March 2010 there 47 clinics, 171 visits, and 85 unique patients. There were 52 new evaluations and 119 follow-up visits. The number of visits ranged from 1–8; length of follow-up ranged from 1 month to 4.5 years. The no-show rate for all VC sessions in 2009 was 3%, and only 2 subjects in 5 years refused further VC visits.

**Conclusion—**Once cultural barriers are dealt with, VC-based diagnosis and treatment of adults with cognitive disorders who live in remote areas is feasible and well accepted by patients and families.

### Keywords

Videoconferencing; dementia

## 1. Background

Dementia has become increasingly a public health concern that, because of the aging of the population, is predicted to more than double worldwide over the next 30 years. (1) The evaluation and management of dementia requires frequent interaction with family members and other caregivers to address caregiving needs, behavioral disturbances, loss of function, and access to community resources such as respite care. It also requires monitoring for



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potential complications that can arise during the course of neurodegenerative disease. Early diagnosis, treatment, and follow-up of dementia patients can reduce health care costs, increase the quality of life for patients, and reduce caregiver burden. [2] Dementia detection in primary care settings remains low [3, 4] and the quality of care for dementia is lower than for other conditions. [5, 6] The dementia diagnostic workup is even more difficult for rural patients, involving consultations with multiple specialists over extended time periods. [7] Limited access to specialists means that responsibility for early diagnosis and treatment will fall on primary care physicians. [8] Rural primary care physicians identify limited access to consultants and limited community support and education resources as major barriers to dementia diagnosis and treatment. [9] The issue of provision of dementia care to persons in rural or other remote settings is now being addressed by videoconferencing (VC).

Substantial progress has been made in VC-based administration of neuropsychological testing to older adults, including the administration of the Mini-mental State Examination and tests of verbal learning, verbal fluency, vocabulary, visuospatial reasoning, attention, and clock drawing. [10, 11, 12] VC evaluation of language has also been performed with AD patients. [13] There is a small literature on the use of videoconferencing (VC) to diagnose and treat cognitive disorders in older adults [14, 15, 16, 17] including a publication on the diagnosis of Alzheimer disease (AD) in persons with Down syndrome. [18] A description of several programs follows.

Morgan and colleagues [17] described the development and implementation over 3 years of a multidisciplinary clinic for rural and remote Canadian patients in which direct patient examination of 137 persons at a tertiary care center was augmented by a pre-clinic and follow up VC interaction between clinic staff and caregivers. VC was compared with face-to-face evaluation in 140 subjects seen over 2 years and rates of agreement in diagnosis ranged from 76–89%. [14] PC-based VC equipment (Cruiser, version 4, VCON) was connected by ISDN lines at 384 kbit/s. Subjects were 20 persons over 65 years of age with good hearing and eyesight who had been referred by general practitioners because of cognitive impairment. Assessment tools included the Standardized Mini-mental State Examination, Geriatric Depression Scale, Katz Assessment of Daily Living, Instrumental ADL Assessment and the Informant Questionnaire for Cognitive decline in the Elderly. Although the direct method included a physical examination by a specialist geriatrician, there were no significant differences in diagnosis between the 2 methods ($\kappa = 0.8$, $p < 0.0001$), and there was good agreement on each of the assessment instruments. Nine subjects were diagnosed as AD on direct examination and 10 on VC evaluation. A similar study comparing face-to-face evaluations by geriatricians with VC diagnosis showed 100% agreement of dementia diagnosis. [16]

The present study reports 5 years using VC technology in diagnosing and treating adult members of the Choctaw Nation who presented with symptoms or complaints of cognitive impairment. Since February 2001, members of the UT Southwestern Alzheimer's Disease Center faculty in Dallas, Texas have operated a federally funded memory clinic at the Choctaw Nation Healthcare Center in Talihina, Oklahoma, in the southeastern part of the state. Our mission was to provide clinical service as a means to obtain longitudinal data for our own research and for the database of the National Alzheimer's Coordinating Center. Our use of VC technology was prompted by logistical and manpower issues. The 3.5 hour travel time by automobile to and from Dallas, Texas to Talihina limited our clinic duration and frequency, causing long waits between referral and evaluation and making it difficult to follow patients closely. We made use of the Choctaw Nation VC network connecting the Choctaw Nation Healthcare Center in Talihina to 3 outpatient clinics. The Choctaw Nation had a 1.5 Mbps connection from the commodity Internet cloud to their firewall. There were Polycom VC setups with 35" monitors in 3 clinics, all connected by a dedicated T-1 to a

video bridge behind their firewall. This network had already enabled interchange of radiologic images among the four sites in addition to VC. Through OneNet, the Oklahoma telecommunications network for education and government, specialty services including eye care, orthopedics, cardiology and diabetes care had become available to the Choctaw Nation.

In January 2005, we began a monthly VC clinic. Using a conference room in the Choctaw Nation Healthcare Center and the Medical Television Studio at UT Southwestern Center, we connected with the Choctaw Nation's VC link using Internet Protocol ITU-T H.323, packet-based multimedia communications systems. The digital VC connection is a bi-directional 384 kb/s made from our campus intranet to the commodity Internet cloud. The Choctaw Nation Healthcare Center has a 1.5 Mb/s connection to the commodity Internet. We initially experienced difficulty with pixilation and both sound and motion delay, but these have largely been eliminated due to improvements in VC technology.

## 2. Procedures

We evaluate and follow persons with memory issues who are self, family, or physician referred. We hold our clinics from 1–5 pm on the 3rd Tuesday of the month. Over the past 5 years, 47 VC clinics have been held. Originally intended as a follow-up clinic, we now do initial patient evaluations by VC as well. When the diagnosis is unclear, subjects can be referred to our periodic in-person clinic for face-to-face evaluation. Our diagnostic criteria include NINCDS-ADRDA criteria for probable and possible AD, [19] NINDS-AIREN criteria for vascular dementia, [20] Neary criteria for frontotemporal dementia, [21] McKeith criteria for dementia with Lewy bodies, [22] Petersen criteria for mild cognitive impairment, [23] and DSM-IV™ criteria for depression. [24]

We do not attempt VC diagnostic evaluations of persons with severe visual or hearing impairment, but we follow such persons once diagnosed if a family member is available. Before patients are seen for their initial visit by our faculty members, an extensive battery of neuropsychological tests and scales for behavioral and global function are administered by trained personnel (we have a full-time nurse and a full-time educator, both living near Talihina) at the Oklahoma site. The battery consists of the CERAD Battery [25] (including the Mini-mental State Examination), [26] clock drawing, [27] Trails A and B, [28] the logical memory subtest of the Wechsler Memory Scale-III, [29] tests of verbal fluency (animal and vegetable), digit span, the Digit Symbol Substitution test, [30] and additional measures for persons with mild impairment. Subjects' overall level of function is assessed with the Clinical Dementia Rating, [31] depression-related symptoms by the Geriatric Depression Scale, [32] and behavioral symptoms by the Neuropsychiatric Inventory. [33]

These tests are administered in Talihina, scored by psychometricians in Dallas, and then reviewed by the VC physician who consults a neuropsychologist as needed. Prior to their first visit, all individuals have CT brain studies (MRI was unavailable in Talihina in the time period covered by this report) and routine blood tests, including folate and B12 levels and a serological test for syphilis, performed in Talihina. Imaging and laboratory results are available to our physicians through access to the Choctaw Nation electronic health record. Our Oklahoma staff offers patients a choice of in-person or VC evaluation. Because of the time interval between our in-person clinics (3–6 months), most choose VC, following an explanation to patients and their families that they will be seen from Dallas on a TV screen. We ask that, when possible, patients be accompanied by someone who knows them well.

Patients are seen in a conference room housing a ceiling-based camera with a zoom feature. Physical observations made by VC include eyesight, hearing, facial expression, gait and station, coordination, tremor, rapid alternating movements, psychomotor activity, and motor

tests of executive function including the Luria maneuver and a reciprocal motor task. Cogwheeling and rigidity are tested by our on-site nurse, who also obtains vital signs as indicated. For persons whom we follow longitudinally out of research or clinical interest, our entire cognitive testing battery is administered yearly, and scores are compared with earlier scores. [34]

## 3. Results

From January 1, 2005 to March 1, 2010 there were 171 VC visits; 85 unique patients were seen. There were 52 new evaluations and 119 follow-up visits. The number of VC visits ranged from 1– 8, with a median of 1 visit and a mean of 2 visits. Most follow-up intervals ranged from one month to one year (Table 1). There were 7 subjects with >1 year between follow-ups; the longest interval was 4 years between visits. Length of follow-up ranged from 1 month to 4.5 years. In recent years, we have had to decide whom to follow because the number of follow-up visits began to limit our availability for new evaluations. As examples, our staff discontinued following 2 persons with cognitive complaints whose testing and VC examination were within normal limits for age, who had no evidence of impaired function in daily life and who showed no evidence of mood disorder. We also discontinued following several persons with stable effects of brain injury who seemed to be managing well. However, patients were assured that we were available for follow-up should they feel the need.

Diagnoses at the time of initial evaluation for persons seen only by VC are indicated in Table 2. Our diagnostic accuracy is uncertain because we lacked autopsy confirmation for patients seen in our VC clinic. However, our clinical diagnosis of AD in Dallas patients was confirmed in 88.6% (147/166) of autopsied cases. [35] We were able to observe our patients over time, and over the past 5 years 12 persons converted from other diagnoses to AD, including 5 persons first diagnosed as non-demented or MCI. No diagnosis of AD was changed over the 5 years.

All subjects with mild cognitive impairment or suspected progressive illness were offered routine yearly follow-up and more frequent clinical visits if needed. There were no refusals of VC for initial visits and 2 refusals of continued VC follow-up. In one case, the patient's suspiciousness precluded further visits; in the other, the patient's son became angry when there was a misunderstanding about the physical location of the visit. In the first case, the patient was followed by telephone contact with her caregiver; there was no further contact in the second. To compensate our patients and their families, the patient and one caregiver are each given a $25 Wal-Mart gift certificate at every visit. Because of the experience of other Choctaw Nation medical clinics with failed appointments, our nurse made a reminder telephone call the week prior to each visit. We did not have a formal satisfaction survey, but our no-show rate for all VC sessions in the past year was 3%.

VC visits were labor intensive. Initial evaluation sessions required approximately 6 hours per person of preliminary work by our Oklahoma staff. We paid for use of staff and studio time at UT Southwestern for our 4-hour monthly sessions, but did not have to pay for the Choctaw Nation equipment or video technician support. We have within the past year been seeing 5–6 persons per session, depending on the number of new evaluations. Our estimated cost per new patient, including the preliminary neuropsychological testing was $275; for follow-up patients, about $130. The estimated cost includes Talihina salaries, Dallas studio time, and physician and support personnel time in Dallas, but does not include the cost of equipment or the $25 each that we pay patients and caregivers or the cost of the laboratory work and imaging studies, which were borne by the Choctaw Nation. With improvement in

technology, our VC costs should reduce somewhat, but the expenditure for personnel seems unlikely to diminish and laboratory and imaging costs will probably not change.

## 4. Discussion

### 4.1 Costs

With improvement in technology, VC costs should reduce significantly, but the expenditure for personnel seems unlikely to diminish and laboratory and imaging costs will probably not change. The expense of VC follow up sessions could be eliminated if local physicians were willing to assume responsibility for ongoing dementia care once the diagnosis was established and a plan of treatment formulated.

### 4.2 Logistical issues

VC did not overcome our patients' major deterrrant to clinic visits, which was transportation. Our patients were mostly rural, and lived over a large area in southeastern Oklahoma. Some did not drive, and there is no public transportation system in southeastern Oklahoma. Some persons could not afford an automobile and others occasionally could not afford fuel.

### 4.3 Cultural issues

From previous work with the Cherokee Nation and the Urban Intertribal Center in Dallas we had learned that based on previous experience, there was a strong concern at the tribal and organizational level about exploitation. [34] Therefore, they had no interest in supporting research without immediate impact on them. They wanted a direct effect on health or quality of life and a positive economic impact on their community. Data gathering was to be done only with the explicit consent of subjects and their confidentiality was to be maintained. In addition, any research findings would be submitted to the tribe or center for approval prior to publication. Based on these requirements, we made clinical care our primary focus with the Choctaws, including our data gathering with clinical care. In addition, we hired tribal members to fill the jobs related to our activities, paid them through the Choctaw Nation, and submitted manuscripts for approval by the Nation.

Our impression is that the cultural barriers among Choctaws are less than what has been encountered with other tribes. [36] The Indians with whom we worked did not live on a reservation and were well acculturated. They were community dwelling, spoke English as their primary language, had an average of 11 years of education and an average 25% Indian heritage. [34] The issues we encountered were primarily related to low income and rural living. Patients could only afford medications such as donepezil that were covered by the Choctaw Nation but could not afford memantine, for which they needed to pay out of pocket. Some of the individuals needed an explanation of the gift certificates.

It was possible to establish working relationships with patients and caregivers using VC technology, but some patients did not understand that they had seen a doctor. Despite this, our 2009 no-show rate was small, possibly due to reminder calls the day before scheduled VC clinic sessions and the gift certificate for patient and caregiver, although patients and families had not been informed of the gift certificates prior to their evaluation. Our link with patients and their families was enhanced by our on-site personnel, and the relationships they established enabled us to recruit more 70 persons for a separate study of VC-based neuropsychological testing.

## 5. Conclusion

VC-based diagnosis and treatment of adults with cognitive disorders who live in remote areas is a feasible alternative to face-to-face care that is well accepted by patients and family members. The rapid development of Internet-based technology will make telemedicine even more readily available and much more affordable for institutions and individual practitioners.

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**Table 1**

Description of Video-conferencing Sample (N=85)

| | | Min | Max | Mean (SD) | Median |
|---|---|---|---|---|---|
| % Female | 53 | | | | |
| Age at First Visit | | 26.64 | 93.02 | 69.67 (12.79) | 70.92 |
| Education | | 5 | 16 | 11.28 (2.41) | 12 |
| Follow-up Visits | | 1 | 8 | 2 (1) | 1 |
| Follow-up Duration in Years | | 0.06 | 4.58 | 1.50 (1.37) | 1.02 |

**Table 2**

Initial Videoconference Diagnosis

| | Frequency | Percent |
|---|---|---|
| Alzheimer Disease | 47 | 55.3 |
| Psychiatric Illness | 12 | 14.1 |
| Mild Cognitive Impairment | 10 | 11.8 |
| Other | 6 | 7.0 |
| Head Trauma | 4 | 4.7 |
| No Dementia | 3 | 3.5 |
| Parkinson's Disease | 2 | 2.4 |
| Stroke/Vascular Dementia | 1 | 1.2 |
| Total | 85 | 100 |