

THE IHS PRIMARY CARE PROVIDER

A journal for health professionals working with American Indians and Alaska Natives



October 1998

Published by the IHS Clinical Support Center

Volume 23, Number 10

Status of Impairments and Functional Limitations of American Indians Residing in a Nursing Home

Robert Sandstrom, PhD, PT, Associate Professor; Michelle Keeler, Student; and Megan Lowdermilk, Student; all from the Department of Physical Therapy, Creighton University, Omaha, Nebraska; and Wayne Tyndall, Health Planner, Carl T. Curtis Health Education Center, Macy, Nebraska

Abstract

Prevention of decline in functional status and mobility is a serious concern in skilled nursing facilities. The purpose of this study is to describe the impairment and functional limitation status of residents in a licensed skilled nursing facility operated by the Omaha Tribe of Nebraska. All the nursing home residents were evaluated using the Physical Therapy Assessment and Treatment Protocol. Fifteen individuals or legal guardians gave informed consent to be included in the data in this report. The most common diagnoses in this population were those reflecting central nervous system dysfunction. A high frequency of impairments in cognitive status, joint flexibility, strength, and balance were found. However, thirteen of the fifteen residents were able to maintain some ability to move about their residence. The implications of these findings on the development of restorative care programs in American Indian nursing homes are discussed.

Introduction

With an expected growth rate of 50% between the years 1980 and 2000, the elderly American Indian and Alaska Native population is the fastest growing ethnic population in the United States. Although comprising about only 6% of the total Indian population, the number of elderly American Indians has increased 69% since 1980.¹ The aging of this population, as with all other populations, raises many issues, such as where these people will live and who will care for them. The health care needs of this population are poorly understood and the

necessity for a comprehensive plan to address their health problems has been advocated.^{2,3} In 1990, the Office of Planning, Evaluation and Legislation of the Indian Health Service sponsored a roundtable meeting that developed an Elderly Long Term Health consensus statement. The roundtable report found that long term care issues for American Indian and Alaska Native (AI/AN) peoples lacked a federal mandate, and the needs of this population had largely been undefined.⁴ A 1997 report of the National Resource Center on Native American Aging at the University of North Dakota found a large unmet need in providing intermediate care facilities, skilled nursing facilities, and short term rehabilitation services.⁵

The limited availability of services and the isolated location of many American Indian elders hinder long term care planning. In contrast to the 19,000 nursing facilities available to the general population in the United States, there are only

In This Issue...

- 133 Status of Impairments and Functional Limitations of American Indians Residing in a Nursing Home
- 137 Assessing Elders' Long Term Care Needs
- 138 Caring for Our Elders
- 140 Concepts of Public Health and Epidemiology
- 140 USPHS PPAC Website
- 141 Call for Papers for 11th Annual IHS Research Meeting
- 142 IHS Research Program Abstract Form
- 143 Focus on Elders
- 144 Indian Aging Conferences and Websites of Interest
- 145 Position Vacancies
- 146 Meetings of Interest

approximately 25 long term care facilities owned and operated by Indian tribes. Within each of these facilities, only between 20 and 96 beds are available.¹ Since as many as 13% of American Indians may need long-term care, only a small fraction can be placed in the few American Indian nursing homes available.

Geography is also a hindrance to long term care. Most reservations are large, and the residents live in relative isolation. Oftentimes, dirt roads become impassable due to inclement weather. This also leads to difficulty in placing an elder in a nursing home, as well as for family members visiting the elder in such a facility.¹

Due to these problems, elders are sometimes placed in non-Indian nursing homes, which may sometimes be closer than the nearest available bed in an Indian nursing home. Mercer has recently reported significant cultural issues, including language barriers, educational differences, and social needs that should be considered when providing services to American Indian elders residing in a nursing home.⁶ An Indian elder might encounter a staff unfamiliar with Indian ways, non-traditional foods, as well as language barriers with the staff and other residents alike. Another source of discomfort is the lack of access to a traditional Indian medicine practitioner, a person respected for spiritual healing within the Indian culture. Taken together, these cultural differences can lead to feelings of loneliness and decreased quality of life, and can increase resident and family dissatisfaction.

Within the American Indian nursing home, physical therapists as well as other health care professionals must be concerned with treating patients with respect for them as individuals and for their culture, and maintaining maximal levels of independence. Within the Indian population, 71% of individuals over the age of 60 have difficulty in the ability to perform activities of daily living (ADLs).¹ Federal law requires all nursing homes to provide services that prevent deterioration of function and promote maximal independence for all residents.⁷ The prevention of any decline in functional performance is one objective for quality long term care services. The OPEL/IHS report cited that functional status “has not been assessed on a comprehensive basis” and that “there is a requirement for more current descriptive data.”⁴

Rehabilitation/restorative care services are one element of care in the nursing home setting. There are conflicting reports regarding the effectiveness of physical therapy services in nursing homes. Wide differences in utilization of rehabilitation services have been reported. Przybylski et al⁸ reported that increasing the level of rehabilitation services had a positive effect on both functional status and the cost of care of long term care residents. Chiodo et al⁹ concluded that only high intensity physical therapy services were effective in a nursing home population. Moseley¹⁰ reported that physical therapy was more effective in preventing regression of ADL function than in producing actual improvement in ADL status. In a randomized trial of nursing home-based physical therapy,

Mulrow et al¹¹ demonstrated only a “modest mobility benefit” for long term nursing home residents.

The mandate to prevent the decline in functional performance and the lack of conclusive evidence for the effectiveness of rehabilitation have made it difficult for policy makers, administrators, and clinicians to develop quality programs. One effort to do so was completed by Thys and Collard in 1995.¹² This demonstration project in Colorado nursing homes resulted in cost savings and improved patient status in skin integrity, mobility, continence, and quality of life when the project was implemented in a comprehensive and team driven format. A three-tiered structure for rehabilitation services was recommended for the skilled nursing setting. Tier One would be formalized therapy services for patients who require the skills of a physical or occupational therapist and who show progress toward identified goals. Tier Two includes residents discharged from formalized services, but who have specific instruction for care from a therapist to be implemented by a restorative aide. Tier Three is for residents who require neither formal rehabilitation or restorative care, but who need routine services to prevent decline in function that can be implemented by a nurse aide.

The Carl T. Curtis Health Education Center (CTCHEC) in Macy, Nebraska is operated by the Omaha Tribe of Nebraska, a federally recognized tribe. Within CTCHEC is a 25 bed skilled nursing facility. In partnership with the Omaha Tribe, CTCHEC, the Winnebago Tribe, and the USPHS IHS Hospital at Winnebago, Nebraska, Creighton University successfully obtained a federal grant (HRSA Grant #D37AH00634-01) to develop a training program for physical/occupational therapist students with the goal to increase the supply of health care practitioners for medically underserved areas. One of the components of this grant is to develop clinical services. One clinical service that is being developed is a restorative care/rehabilitation program for residents of the CTCHEC nursing home.

Purpose

The purpose of this study is to describe the restorative care needs of the residents of the Carl T. Curtis Health Education Center nursing home. This study is part of a larger project to describe changes in functional status over time in American Indian residents in a nursing home setting and to develop effective strategies to prevent avoidable functional status decline in this population.

Methods

The subjects for this study were residents of the Carl T. Curtis Health Education Center nursing home in Macy, Nebraska, all of whom were American Indians representing Northern Plains Tribes. All of the subjects received a physical therapy evaluation per standard clinical protocol. Of the residents, 15 individuals or legal guardians gave consent for their data to be included in this report. The informed consent

process and the study procedure were approved by the Creighton University Institutional Review Board for the Protection of Human Research Subjects.

In order to determine the restorative care needs of this population, we utilized the Physical Therapy Assessment and Treatment Protocol developed by O'Neil, et al.¹³ This method was developed specifically for use in skilled nursing facilities and has been shown to have good interrater reliability and face validity. This tool measures strength, muscle reflex activity, locomotion, sensation, soft tissue status, balance/coordination, posture, ADL function, bed mobility, and skin integrity, as well as general behavior, communication skills, and mentation. Impairment or functional status thresholds have been defined for each test. In addition, the Folstein Mini-Mental State Examination was used to further assess cognitive function. Due to the impaired cognitive status of many residents, we decided to omit the sensory testing component of the PTATP. All of the assessments were completed by one of the authors (RS).

Simple descriptive statistics were calculated and are reported for the demographics of the sample and each of the major categories of the PTATP.

Table 1. Primary and secondary diagnoses of nursing home residents

Primary
Central Nervous System
Stroke (4)
Quadriplegia
Organic Brain Syndrome
Parkinsonism
Schizophrenia
Korsakoff's Syndrome
Closed Head Injury
Other
Chronic Renal Failure (2)
Cancer
Lower Limb Fracture
Above Knee Amputation
Diabetes Mellitus
Secondary
Cardiopulmonary
Congestive Heart Failure (3)
Chronic Obstructive Pulmonary Disease
Other
Depression
Abdominal Aortic Aneurysm
Osteoarthritis
AV Fistula
Dementia
Lower Limb Fracture
Diabetes Mellitus
Chronic Renal Failure

Results

Eight males and seven females gave informed consent to participate in the study. Ages of the study participants range from 44 to 90 years, with the average age being 66.7 years. Primary and secondary diagnoses are listed in Table I. The most common primary diagnoses were central nervous system dysfunctions including stroke (n=3), quadriplegia, organic brain syndrome, Parkinsonism, schizophrenia, Korsakoff's syndrome, and closed head injury. The most common secondary diagnoses were cardiopulmonary dysfunction including congestive heart failure (n=3), and chronic obstructive pulmonary disease.

Functional Status

Locomotion. Locomotion was defined as the ability to ambulate or use a wheelchair to self-propel down a hallway up to 150 feet. Twelve of the 15 subjects were able to locomote some distance with or without assistance. Two residents were unable to locomote at all. One resident was not tested due to a recent fracture. Nine of the subjects could complete the 150 foot distance. Of these 9 individuals, 3 used a wheelchair, 3 individuals ambulated with an assistive device, and 3 individuals ambulated independently. Of the 12 subjects capable of wheelchair locomotion or ambulation, 8 were independent in the task.

Transfers. The burden of care to perform a wheelchair to mat transfer was assessed. Of the 15 subjects assessed, 6 residents were independent, 5 residents required less than fifty percent assistance, and 2 residents required greater than fifty percent assistance. Two subjects were totally dependent in transfers.

Bed Mobility. The burden of care to roll to the side and sit from a supine position on a mat table was assessed. Of the 15 subjects assessed, 8 residents were independent, 3 required less than fifty percent assistance, 3 required more than fifty percent assistance, and 1 was totally dependent with bed mobility.

Impairments

Cognitive Status. The mean score on the Folstein Mini-Mental State Examination was 17.8 out of a maximum score of 30, with a range of scores from 0 to 29.

Range of Motion (ROM). Upper extremity ROM was within normal limits for 7 of the 15 subjects. Lower extremity ROM was within normal limits for 11 of the 15 subjects.

Strength. Upper extremity strength was within normal limits for 5 of the 15 subjects and lower extremity strength was within normal limits for 7 of the 15 subjects.

Soft Tissue. Soft tissue was examined for swelling and skin integrity of the upper limbs, lower limbs, and trunk. Six of the 15 subjects had disruption of skin integrity and 1 individual had lower limb edema.

Balance. Achievement of sitting and standing balance was assessed. In order for the subject to achieve a full score for static sitting, he or she must static sit for at least 30 seconds. In contrast, for dynamic sitting, the patient must complete one of the two following tasks: reaching across midline, or reaching

down to touch the ipsilateral foot.

For static and dynamic standing, the patient must complete two of the three tasks they are asked to perform in each category. For static standing the three tasks include: standing with eyes open for 30 seconds, standing with eyes closed for 30 seconds, and tandem standing. For dynamic standing, the patient is asked to step forward, reach to the floor, and turn 360°. Thirteen of 15 residents were able to perform static sitting balance, while 10 of 15 were able to perform dynamic sitting balance tasks. Eight subjects are able to perform static standing balance while only 4 were able to perform dynamic standing balance tasks. One subject refused to perform the dynamic standing tests.

Discussion

The results of this study describe a range of impairments and functional limitations that must be considered when planning a program of restorative care in a long term care facility. It is difficult to compare these results to other findings from other skilled nursing facilities because of the paucity of the research data and the small sample size of this study. It is apparent that multiple impairments and functional limitations exist and would challenge the staff of a long term care facility in the absence of professional direction and support to devise an effective program and treatment plans.

The presence of cognitive dysfunction and the high frequency of central nervous system pathology indicate a serious and permanent level of disability in this population. Over fifty percent of the subjects had joint flexibility or limb strength impairments. Only twenty-five percent of the subjects were able to perform two of three simple standing balance tasks. One in three patients could not perform the simple tasks of reaching across the midline or reaching down to their shoes in the sitting position.

Given the frequency of these impairments in the musculoskeletal and balance systems, it is remarkable that 13 of the 15 residents could participate in or complete a locomotion task. Six of the thirteen residents could ambulate the 150 foot test distance; of these, 4 individuals did not need an assistive device. It is apparent, however, that some individuals are at risk of losing ambulation function.

Table 2. Standing ability and ambulation distance for ambulatory nursing home residents

No.	Dx	Amb.Dis.	Static Stand	Dyn. Stand	LE Str	UE Str
2	CVA	10 ft.	NO	NO	IMP	IMP
3	CRF	150 ft.	YES	YES	WNL	IMP
4	CA	150 ft.	YES	YES	WNL	WNL
5	OBS	12 ft.	NO	NO	IMP	IMP
6	CRF	58 ft.	YES	YES	IMP	IMP
7	PARK	150 ft.	YES	YES	IMP	IMP
13	DM	150 ft.	YES	NO	WNL	WNL
14	SCHIZ	150 ft.	YES	NO	WNL	WNL
15	KORSA	150 ft.	YES	YES	WNL	WNL

Table 2 summarizes the descriptions of the 9 residents who could ambulate at the time of the evaluation. We believe that subjects 2 and 5 are at great risk for losing the ability to ambulate. They are currently unable to stand independently and complete the standing balance tasks, and can ambulate less than 15 feet even with assistance. Subjects 6 and 7 are at moderate risk for losing the ability to ambulate, but we believe they can maintain their function with restorative care, barring a new, adverse event. Subjects 13 and 14 appear to have low risk for deterioration of ambulation function but may have an elevated risk for falls due to a failure to complete the dynamic balance tasks. Subjects 3, 4, and 15 are stable, independent ambulators; we are continuing surveillance of this group to assess their needs and determine the predictive validity of our pilot model.

These data demonstrate a need for restorative care services in nursing homes. The project is continuing with ongoing surveillance and consultation regarding the mobility and locomotion status of the residents of this facility. It is hoped that through identification of individuals at risk for deterioration in functional status and who might benefit from early intervention, the process of declining functional status may be slowed or halted. Second, it is hoped that a process of restorative care can be established and described — a process that is culturally sensitive and meets the real challenges of providing these services in American Indian communities. We are interested in communicating with other individuals and facilities interested in these needs. Please contact Dr. Robert Sandstrom, Department of Physical Therapy, Creighton University, 2500 California Plaza, Omaha, NE 68178; phone (402) 280-4325; or e-mail rsandstr@creighton.edu. □

References

1. Mercer SO. Navajo elders in a reservation nursing home: health status profile. *J Gerontol Soc Work* 23:3-29, 1994
2. Manson SM. Long term care in American Indian communities: issues for planning and research. *Gerontologist* 29:38-44, 1989
3. Manson SM. Provider assumptions about long term care in American Indian communities. *Gerontologist* 29:355-358, 1989
4. Office of Planning, Evaluation and Legislation, *Indian Health Service. Elderly Long Term Health Consensus Statement.* Indian Health Service, Rockville MD, 1990
5. Ludtke RL, Pan S. Housing needs for Native American elders. [Internet source] Available at: <http://www.und.nodak.edu/dept/nrcnaa/fs7.html>. Accessed July 20, 1998
6. Mercer SO. Navajo elderly people in a reservation nursing home: admission predictors and cultural care practices. *Soc Work* 41:181-189, 1996
7. Omnibus Budget Reconciliation Act of 1987, Subtitle C. Nursing Home Reform Act, PL 100-203, 1987
8. Przybylski BR, Dumont ED, Watkins ME, et al. Outcomes of enhanced physical and occupational therapy services in a nursing home setting. *Arch Phys Med Rehabil* 77:554-561, 1996
9. Chiodo LK, Gerety MB, Mulrow CD, et al. The impact of physical therapy on nursing home patient outcomes. *Phys Ther* 72:168-173, 1992

- Retirement homes
- Board and care facilities
- Sheltered care
- Life care or continuing care communities

Depending on the level of care offered, individuals living in such facilities may receive housekeeping services and meals, minimal assistance with daily needs, dispensing of prescription medications, and some periodic health care from a nurse and/or physician.

Residential Care

When independent living is not an option, whether for brief or extended periods, the options are as follows:

- Intermediate Care Facility
- Skilled Nursing Facility
- Rehabilitation Facility
- Hospital-Based Skilled Nursing Facility
- Swing beds
- Subacute Care
- Long-Term Care Hospital
- Acute Hospital Care

Case Report

Agnes S. was an independent, if somewhat stubborn and feisty woman of 80 years' wisdom. She lived alone in traditional housing in a small reservation community about 50 miles from the IHS hospital. She was what the doctors referred to as "frail" in that she had poor balance, had mild dementia, didn't eat very well, and was thin and chronically poorly nourished. Her daughter lived nearby and provided her with groceries, water, firewood, and transportation when she needed to go into town or to the clinic, although the daughter's own family and work responsibilities kept her from visiting as often as she wished she could. Agnes like to attend social gatherings and activities at the senior center, but transportation was a problem. She received no home delivered meals or any other in-home services beyond what her daughter provided.

Unfortunately, one evening on her way outside she tripped and fell. Her broken hip kept her from getting up, and there was little she could do but lie there and wait. That following evening when her daughter arrived, she found her unconscious, cold, and dehydrated.

She was transferred from the local IHS facility to a tertiary center where she had a total hip replacement. A large decubitus ulcer formed following her prolonged immobility

after her fall. Unfamiliar with her home situation, the discharge planner at the tertiary center was at a loss as to how to arrange her postacute care.

She was transferred to the IHS facility near her home so that they could coordinate her care. The family physician there felt that she needed nutritional support and care for her pressure sore, but that this did not have to be done in the hospital, yet could not be done at home. A temporary stay was arranged in a nearby skilled nursing facility. Within two weeks, she was ambulatory, her pressure sore was almost healed, and her nutritional status was improving.

The Public Health Nurse made a home visit and worked with her daughter to improve the safety of the home. Visits to monitor her recovery and well being were arranged with the CHR. A church-affiliated home health care agency was contacted and they were able to provide home nursing and physical therapy until her ulcer was completely healed and her strength was back to normal. She was put on the priority list for tribal congregate housing in the seniors project and it was anticipated that she would move into a comfortable apartment within six months. The tribal seniors program began delivering a noon meal three times a week and was able to bring her to congregate meals followed by social activities the other two days during the work week.

Her case and others similar to it raised the sensitivity of the family practice physicians and the public health nurses who established an Elders Committee to work with the Tribal Health Board to try to establish some of the services that would be helpful to Agnes and others like her. They began with a volunteer group to make "friendly visits" to check on the welfare of Agnes and others, but this was just the first step in an ambitious plan they envisioned for the future.

Conclusion

The environments and services that make up the continuum of care in a remote reservation community may seem different from those in an urban community. They may be organized differently, payer sources may not be the same, and a good deal of innovation may be involved, but they will serve the same purposes. Cooperation between health care providers, the tribe, the community, elderly individuals, and their families and caregivers will be the key to obtaining, organizing, and accessing these services. Providers should be prepared to discuss these issues with elderly patients or with those who are responsible for the care of older relatives. □



Caring for Our Elders: The Continuum of Care in the Community

John F. Saari, MD, Geriatrician and Family Practice Physician, Phoenix Indian Medical Center, and Physician Educator, IHS Clinical Support Center, Phoenix, Arizona

Introduction

In the August issue of *The IHS Provider* (Volume 23, Number 6, pages 109-111), Miller and Finke presented a clear explanation of the concept of “swing beds.” There are misconceptions about what swing beds are, and so it was extremely useful to learn more about them. In this article, we will back up a step and present an overview of the whole spectrum of care that applies to our elders in Indian Country, or anywhere, for that matter.

Often, there is an assumption that the choices for care for the elderly are limited to home, the hospital, and the nursing home. While not all of the options described in this article are found in all communities, and there are certainly differences between urban and reservation settings, it is important that we all — care givers and care users alike — know what is or should be available. If any given service is not available in a community, then perhaps this is an opportunity for health care planners, providers, and consumers to join together to advocate for services that should be developed. This may include everything from simply finding out how to access a given service in your community to establishing new programs.

It is also important for care users — both elderly individuals interested in their own options and care givers who look after an elderly friend or relative — to examine community resources **when they don’t need such services**, since to try to do so when in a crisis situation can be an overwhelming experience.

A Continuum

The continuum of care is just that: a range of assistance that begins with the community living, independent elderly, going through a spectrum of environments and services that culminates at the other extreme, in an acute care hospital. In general, as you move along the spectrum, you go from least to most, in terms of cost, intensity of care, and restrictiveness of the environment. Overall, the goal is to “move” any individual receiving services from the most intensive (restrictive) to the least. Sometimes it is a happy surprise that an elderly person in the continuum will “leapfrog,” skipping one or more levels, on the road to rehabilitation, recovery, and independence; other times, it is crucial to take each “step” in order to assure progress and avoid adverse outcomes. Therefore it is important for providers and consumers alike to be familiar with each

element of the continuum.

Home Services

Elderly individuals living at home may find need for any number of the following services found or used outside the home:

- Transportation
- Nutrition (congregate meals)
- Recreation and socialization
- Outpatient health care
- Counselling
- Information and referral
- Senior centers
- Day care, day hospitals

Those living at home may also require some of the following in-home services:

- Monitoring of well being and emergency response to calls
- Homemaker or assistance with chores and home maintenance
- Nutrition (“Meals on Wheels”)
- Home health care
- Case management
- Caregiver assistance
- Respite care for family members
- Adult Protective Services

Most of these services can be provided on an informal basis by friends or extended family when the situation permits, by church or civic club members, by Community Health Representatives or Public Health Nurses, or by tribal services (Chapter Houses or tribal assistance programs). Charitable organizations, non-profit community organizations, municipal, county, or state agencies, or Area Agency on Aging programs are other potential resources. IHS or tribal hospitals and clinics with their family practice physicians, social services departments, and community health programs are also helpful.

Assisted Living

When an individual can no longer live alone or with family in the home, semi-independent living arrangements are often the next step along the continuum. These include the following:

- Congregate housing
- Adult foster homes

When more assistance is needed, the following options should be considered:

- Residential care homes

-
10. Moseley CB. Rehabilitation effectiveness among long term nursing home residents. *Phys Ther Occup Ther Geriatr* 14 (4):27-41, 1996
 11. Mulrow CD, Gerety MB, Kanten D, et al. A randomized trial of physical rehabilitation for very frail nursing home residents. *JAMA* 271(97):519-524, 1994
 12. Thys J, Collard BJ. Improvement of rehabilitation nursing services to the elderly in long term care facilities in Colorado. Grant #08AM0050/01 from the National Institutes on Aging, Office of Human Development Services, Department of Health and Human Services, Final Report, 1995
 13. O'Neil MB, Woodard M, Sosa V, et al. Physical therapy assessment and treatment protocol for nursing home residents. *Phys Ther* 72:596-604, 1992
-

Assessing Elders' Long-Term Care Needs in the Santa Fe Service Unit

Catherine H. Hennessy, DrPH, MA, Epidemiologist, Health Care and Aging Studies Branch, Centers for Disease Control and Prevention (CDC), Atlanta, Georgia; and Robert John, PhD, Director, Minority Aging Research Institute, Northeast Louisiana University, Monroe, Louisiana

The Health Care and Aging Studies Branch (HCASB), located in the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, conducts research on the health and health care needs of older adults. As part of these activities, the HCASB provides technical assistance and research support to the IHS on the long-term care needs of American Indian elders. Working in collaboration with the Minority Aging Research Institute (MARI) at Northeast Louisiana University, the HCASB has carried out studies profiling the service needs of elders and their family caregivers among several tribes in the Southwest and Oklahoma.

A recently completed report, "Long-Term Care Service Needs of American Indian Elders in the IHS Santa Fe Service Unit," provides recommendations for developing the continuum of geriatric care for the eleven Pueblo Tribes in the service unit. According to the 1990 U.S. Census, there are approximately 1,400 Pueblo elders age 55 and over in the Santa Fe Service Unit. As elsewhere in Indian Country, the health and support services available to these elders lack a geriatric focus and do not adequately address the chronic care needs of functionally impaired elders. In the absence of in-

home and community-based long-term care, family members are often the primary providers of needed assistance with medical regimens and activities of daily living.

To document the nature and extent of long-term care needs in the Santa Fe Service Unit, the researchers conducted an assessment consisting of four components: 1) a survey of elders' health and functional status, service utilization, and perceived service needs; 2) a survey of the situation and service preferences among family caregivers providing assistance to frail elders; 3) focus group discussions with family caregivers to further explore caregiving issues and problems; and 4) interviews with service providers to document health and social services currently available to elders in the service unit.

Four priority recommendations for health and support services to elders emerged from the study findings: 1) develop formalized geriatric assessment; 2) expand and integrate existing case management functions; 3) secure or expand the capacity to provide in-home and community-based support services; and 4) develop family caregiver training. Specific programmatic suggestions for implementing these service innovations in ways that are cost-effective and culturally appropriate are also described.

The report is scheduled to be published by CDC in the fall of 1998. For information about obtaining a copy of the report, contact Dr. Catherine Hennessy, Health Care and Aging Studies Branch, Mailstop K-45, Centers for Disease Control and Prevention, 4700 Buford Highway, N.E., Atlanta, Georgia 30341. □



Concepts of Public Health and Epidemiology in Diabetes Prevention for American Indian Tribal Groups

The Johns Hopkins Tribal Education Program (JHTEP) faculty has designed a community-based training and education program in diabetes and diabetes prevention. Its objective is to strengthen the capacity of American Indian tribes to apply public health concepts and epidemiology in primary, secondary, and tertiary prevention of diabetes and its complications. The goal is to combat the emerging and pervasive diabetes epidemic, the fourth leading cause of death among Indians, and support the development of community-based diabetes prevention programs in Indian communities.

The three-day, community-based workshop focuses on diabetes and diabetes prevention. This workshop leads local tribal health personnel in drafting a health plan that will focus on prevention of diabetes by providing relevant background information and guiding participants in collection and analysis

of local diabetes data.

In addition to the workshop, faculty will assist in 6 and 12 month follow-up evaluations and provide technical assistance as needed during a one-year period. The desired outcome is to initiate programs in the local community that address diabetes risk factors, track local diabetes data and, ultimately, to reduce the rate of diabetes. The IHS Clinical Support Center is the accredited sponsor. Tribal and IHS personnel from all health care-related backgrounds and/or who are involved in health care are encouraged to participate.

For additional information please contact Dr. Maha Asham at Johns Hopkins Center for American Indian Health, 621 N. Washington St., Baltimore, MD 21205; phone (410) 955-6931; fax (410) 955-2010; or e-mail masham@jhsph.edu.

USPHS Physicians Professional Advisory Committee Announces New Website

The USPHS Physicians Professional Advisory Committee (PPAC) to the Office of the Surgeon General is pleased to present their new website located at www2.ihs.gov/ppac. The goal of this new site is to enhance communication between both Commission Corps and Civil Service physicians in all operating divisions and major programs of the United States Public Health Service, the physicians PAC members, and the Office of the Surgeon General. This website has many features designed to facilitate a two-way exchange of information, including a threaded Discussion Board, contact information and e-mail links to the physicians PAC members within each operating division, important news and announcements, meeting dates with minutes, and numerous reference links to medically important websites.

Please take a moment to look up this useful website and bookmark it to your list of favorites. Furthermore, if you have news or announcements that are of national importance to USPHS Commission Corps and Civil Service physicians which you would like to have posted, please send them to:

CAPT Timothy D. Mayhew, MD
Chief of Staff
Dzilth-Na-O-Dith-Hle IHS
6 RD 7586
Bloomfield, NM 87413
tmayhew@navsra.navajo.ihs.gov
Phone (505) 632-1801 Ext. 121
Fax (505) 632-0542



Palliative Medicine, Intractable Pain, and End of Life Care

Emerging Issues In Native American Elder Health Care

Judith A. Kitzes, MD, MPH, Chief Medical Officer, Albuquerque Area Indian Health Service, Albuquerque, New Mexico

Diseases and conditions affecting Native American elders are changing as their longevity increases. For Native Americans 55 years of age and older, life expectancy has increased 20 percent between 1972-74 and 1990-92, from 61.0 years to 73.5 years. The leading causes of death for elders in the age group 55-64 years are diseases of the heart, malignant neoplasms, injuries, and chronic liver disease and cirrhosis. In contrast, Indian elders age 65 and older are more likely to die of diseases of the heart, malignant neoplasms, and cerebrovascular diseases.¹ In addition, Native Americans experience a disproportionately high death rate from diabetes mellitus, 41.1 (adjusted death rate per 100,000, 1991-1994), as compared to the U.S. all races rate of 12.4.²

Native American Elders Living Longer

Like all elders in the general population, Native American elders may experience extended periods of chronic illness and disability, sometimes associated with intractable pain, dyspnea, weakness, fatigue, nausea and vomiting, bowel problems, skin conditions, mouth problems, lymphedema, ascites, confusion, dementia, anxiety, or depression. The end of life experience for Native American elders mirrors that of the general population in that it is commonly extended, takes place away from family and the home, and is superseded by a technological, professional, and institutional process of treatment for the dying. Fortunately, new fields of medicine are developing to meet the needs of the elderly faced by the changing epidemiology of chronic disease.

Palliative Medicine

Palliative medicine, first recognized as a medical specialty in 1987 in Great Britain and Ireland, is the “study and management of patients with active, aggressive, far-advanced disease for which prognosis is limited and the focus of care is quality of life.”³ The World Health Organization defines palliative medicine as “the active, total care of patients whose disease is not responsive to curative treatment . . . (when)

control of pain, of other symptoms, and of psychological, social, and spiritual problems are paramount.”⁴

Palliative medicine focuses on the relief of suffering. As a specialized field it has several unique characteristics:

- seeks to prevent, relieve, reduce, or soothe the symptoms of disease without effecting a cure
- not restricted to those who are dying or those enrolled in hospice care
- important adjunct to life-prolonging therapies by relieving pain and other symptoms that are side effects of difficult treatment regimens
- important to those who live with chronic pain or other symptoms
- encourages assessment of pain as a fifth vital sign

Intractable Pain Management

Intractable pain management has grown out of the practice of palliative medicine as a specialized subset of challenges for the practitioner. Intractable pain is pain, the cause of which cannot be removed or otherwise treated and for which no relief or cure has been found after reasonable efforts. Intractable pain is a self-reported diagnosis. The term encompasses pain due to cancer as well that due to other diseases, such as arthritis, end-stage renal disease, fibromyalgia, scleroderma, and chronic obstructive pulmonary disease.

For the past three decades it has been recognized that many patients receive far less than optimal management of their pain. There is a growing body of evidence that unrelieved pain carries with it great physiological and psychological risks, including increased metabolic rate, blood clotting, water retention, impaired immune function, anxiety and depression, loss of hope, and even risk of suicide. Aggressive pain prevention and control can yield both short- and long-term benefits, using both pharmacologic and non-pharmacologic therapies. Well developed algorithms and guidelines are available for pharmacologic treatments and monitoring of their side effects. Unfortunately many elders and their health care providers are fearful of the “myth of opioid addiction” in the treatment of pain. In addition, many third party payers or rigid state pharmacy board regulations regarding the use of high dose opioids cause barriers to effective treatment of pain.

End of Life Care

As stated in the 1997 Institute of Medicine report, "Approaching Death, Improving care at the End of Life":

Dying is at once a fact of life and a profound mystery. Death comes to all, yet each person experiences it in ways that are only partly accessible to the physician or family member, philosopher, or researcher. In principle, humane care for those approaching death is a social obligation, as well as a personal offering from those directly involved. In reality, both society and individuals often fall short of what is reasonably — if not simply — achievable. As a result, people have come both to fear a technological over-treatment and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress.⁵

The body of knowledge related to the dying process has expanded. With the advent of hospice care and palliative medicine, the care of the dying can be an integral and important part of health care, which takes into consideration the needs of the patient and their families and close relationships, and sensitivity to their culture, values, and resources.

End of life care includes advanced planning, ambulatory palliative medicine resources, bereavement services, spiritual support, home care and hospice programs, specialized inpatient palliative care for severe symptoms, and respite care to relieve families caring for a loved one experiencing a long terminal illness.

Conclusion

In summary, the emerging practices of palliative medicine, intractable pain management, and end of life care offer the potential for enhancing the quality of life for Native American elders. Future articles will highlight advances in each of these areas and describe opportunities for implementing these services in the Indian Health Service and tribal programs. As caretakers, health care providers, family members, or members of organizations, we can help reduce preventable suffering by providing care beyond cure. □

References

1. Trujillo M, Nolan L, McClosky R, D'Angelo A. *Indian Health Focus: Elder Care*. Rockville, MD: US Department of Health and Human Services, Indian Health Service, Office of Planning, Evaluation, and Legislation, Division of Program Statistics Publication; March 1996
2. *Indian Health Service Regional Differences in Indian Health — 1997, Charts and Tables*. Rockville, MD: US Department of Health and Human Services, Indian Health Service, Office of Public Health, Division of Community and Environmental Health, Program Statistics Team; April 1998
3. Doyle, et al. Speech to the Association of Palliative Medicine of Great Britain and Ireland, 1993, as cited in: Field M, Cassel C, ed. *Approaching Death: Improving Care at the End of Life*. Institute of Medicine. Washington, DC: National Academy Press; 1997
4. WHO. Definition of Palliative Medicine, 1990, as cited in: Field M, Cassel C, ed. *Approaching Death: Improving Care at the End of Life*. Institute of Medicine. Washington, DC: National Academy Press; 1997
5. Field M, Cassel C, ed., Institute of Medicine, *Approaching Death, Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997

INDIAN AGING CONFERENCES AND WEBSITES OF INTEREST □

Here are four great Websites with information about geriatric conferences. They all have extensive conference listings well into the future and a host of other aging related information for health professionals.

American Geriatric Society (AGS): www.americangeriatrics.org

Gerontological Society of America (GSA): www.geron.org

American Association for Geriatric Psychiatry (AAGP): www.aagppa.org

American Society on Aging (ASA): www.asaging.org

The American Society on Aging is a large multidisciplinary organization of professionals working with and on behalf of older people. They also have an emphasis on multicultural aging. The website includes information from the ASA Journal, *Generations*, news on aging issues, lots of links, and information about special projects of the ASA.



Change of Address or Request for New Subscription Form

Name _____ Job Title _____

Address _____

City/State/Zip _____

Worksite: IHS Tribal Urban Indian Other

Service Unit (if applicable) _____ Social Security Number _____

Check one: New Subscription Change of address

If change of address, please include old address, below, or attach address label.

Old Address _____

THE IHS PRIMARY CARE PROVIDER



The Provider is published monthly by the Indian Health Service Clinical Support Center (CSC). Telephone: (602) 640-2140; Fax: (602) 640-2138; e-mail: provider@smtp.ihs.gov. Previous issues of *The Provider* (beginning with the December 1994 issue) can be found on the CSC Internet home page (<http://www.csc.ihs.gov>).

Wesley J. Picciotti, MPA *Director, CSC*
John F. Saari, MD *Editor*
Thomas J. Ambrose, RPh
E.Y. Hooper, MD, MPH *Contributing Editors*
Cheryl Boshane *Production Assistant*
Erma J. Casuse, CDA *Dental Assisting Training Coord.*
Mary Beth Kinney, MPH, EdD *Dental Ed. Spec.*
M. Kitty Rogers, MS, RN-C *Nursing Consultant*
Edward J. Stein, Pharm D *Pharmacy Consultant*

Opinions expressed in articles are those of the authors and do not necessarily reflect those of the Indian Health Service or the Editors.

Circulation: The Provider (ISSN 1063-4398) is distributed to more than 6,000 health care providers working for the IHS and tribal health programs, to medical and nursing schools throughout the country, and to health professionals working with or interested in American Indian and Alaska Native health care. If you would like to receive a copy, send your name, address, professional title, and place of employment to the address listed below.

Publication of articles: Manuscripts, comments, and letters to the editor are welcome. Items submitted for publication should be no longer than 3000 words in length, typed, double-spaced, and conform to manuscript standards. PC-compatible word processor files are preferred. Manuscripts may be received via the IHS Banyan electronic mail system.

Authors should submit at least one hard copy with each electronic copy. References should be included. All manuscripts are subject to editorial and peer review. Responsibility for obtaining permission from appropriate tribal authorities and Area Publications Committees to publish manuscripts rests with the author. For those who would like more information, a packet entitled "Information for Authors" is available by contacting the CSC at the address below or through our fax retrieval service. Call 602-640-2140, ask for the fax retrieval service, and request document #3005. After business hours, press 8, and follow the instructions.

Dept. of Health and Human Services
Indian Health Service
Clinical Support Center
1616 East Indian School Road, Suite 375
Phoenix, Arizona 85016

BULK RATE
Postage and Fees Paid
U.S. Dept. of Health & Human Services
Permit No. G-290

ADDRESS CORRECTION REQUESTED

OFFICIAL BUSINESS
PENALTY FOR PRIVATE USE \$300