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UNDERSERVED POPULATIONS (H FERNANDEZ, SECTION EDITOR)

Toward Generational Improvement in Native Elder Health

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Abstract

Purpose of Review Older American Indians and Alaska Natives (AI/AN) are a diverse, rapidly growing population; there is a paucity of data in the literature specific to this population.

Recent Findings AI/AN elders represent a relatively small proportion of the overall AI/AN population, carry a high burden of chronic conditions and disability, and suffer disparate impact of social determinants of health. Most but not all of the burden of illness and disability has its origin earlier in the lifespan.

Summary There is a small set of high leverage actions that can be taken in clinical care, public health, and long-term services and supports to improve the health status of current elders. These efforts will build on the strengths and capabilities in tribe and community. Ultimately, the path to healthier AI/AN elders in the future is through investing resources to ensure that the AI/AN population is healthier across the lifespan.

Keywords American Indian/Alaska Native · Health status · Elder · aging · Long-term services and supports · Disparities

Introduction

In 1978, the Association of American Indian Physicians produced a report for the Indian Health Service entitled "Aging: Its Impact on the Health of American Indians". Focusing on the physical and mental health of older American Indians, the report reviewed US Census data and ambulatory care data from the Indian Health Service, noted gaps and inadequacies, and set forth a modest, pragmatic set of recommendations based on their findings [1]. It was not the first such effort, although it may have been the first to be produced by an organization of American Indian physicians in the relatively new era of self-determination and tribal self-governance [2•]. With hindsight, a reader can see in the set of recommendations in the report an agenda reflecting the focus of efforts in Indian Health over the ensuing decades as well as strategies still requiring attention. This paper aims to build on this effort, to understand the current health status of older American Indians and Alaska Natives through a selected literature review with the goal of identifying a set of actions that will, in the coming years, improve the health and wellness of current and future elders.

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The Social, Political, and Cultural Context of Native Elder Care

Any discussion of the health and health care of Native Elders in the USA requires a common understanding of the population under discussion and of the way that population is defined.

Multiple different terms are used for indigenous elders in the USA; most indigenous individuals refer to themselves by their tribal name (or names in the case of multiple tribal affiliations) and often by a clan, community, or other subgroup within their tribe, nation, or village. The definitions most often used in epidemiologic and health services research are those derived from the US Census Bureau (Census) and the Indian Health Service (IHS), an agency within the US Department of Health and Human Services with responsibility for delivery of health services to American Indians and Alaska Natives [3]. The Census defines an American Indian or Alaska Native (AI/AN) as "a person who has origins in any of the aboriginal peoples of North and South America and who maintains tribal

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affiliations or community attachments" [4]. The Census does not further define the nature of the tribal affiliation or community attachment; that determination is left to the Census respondent [4]. The Census also allows respondents to identify as a member of more than one Census-defined group; thus an individual can be self-identified as AI/AN or AI/AN plus another ethnic group [4]. In contrast, IHS population data is linked to eligibility for services, largely defined through enrollment status in a federally recognized tribe, with enrollment defined by the tribe, not by the IHS [5]. In 2010, the Census identified approximately 5.2 million individuals reporting as AI/AN alone or in combination with other ethnic groups and 2.9 million individuals reporting as AI/AN alone [4]. In 2015–2018, the IHS served 2.3 million AI/AN individuals who were enrolled members or descendant from enrolled members of 573 federally recognized tribes [6].

Similarly, there is not a single definition of what it means to be an AI/AN elder. The term "elder" can refer to an age-defined group, to a cultural or religiously significant role in the tribe or community, or to those eligible to participate in specific services targeting older AI/AN individuals. Health data regarding AI/AN elders most often uses the common standard of age 65 and older; social services data not uncommonly extends the range downward to age 50 or 55. Title VI of the Older Americans Act determines funding levels for tribal aging services based on the number of enrolled tribal members who are age 60 or older but tribes may serve younger individuals [7]. Tribes often explain the use of a lower age definition for elder status by the high prevalence of chronic conditions and shorter life expectancy of AI/AN people.

While, as a cohort, AI/AN elders are highly diverse in culture and experience, there are some observations that can be generalized. Current AI/AN elders came of age at a time when there was no real social benefit and often great social harm in being identified as Native within the larger culture [2•]. Elders have grown up with an understanding of trauma and loss associated with the appropriation of land, and loss of livelihood, opportunity, and life resulting from federal and state policy directed toward Native peoples [2•, 8–10]. The current generation of AIAN Elders served in the US military at high rates in comparison to other identified subgroup of Americans [11]. AI/AN elders have lived a life navigating to varying degrees between mainstream culture and a tribal or community culture that is distinct, structured, and often not visible to those outside of tribe or community. Finally, most AI/AN elders living in tribal areas have experienced impaired access to health care and other services and a high degree of exposure to federal bureaucratic structures governing education and health care delivery. They have also, in their adulthood, experienced (and often led) increasing tribal self-governance and control over many of these institutions [2•].

The Indian Health System

A full understanding of the health status of AI/AN elders also requires familiarity with the unique organization and financing of the Indian health system in which a large proportion receive care. Although the system has its origins in an entirely federally operated health system, Tribes now own and operate their own health services through negotiated self-governance agreements utilizing over 60% of appropriated funding for the Indian Health Service [6]. Both IHS and tribal health programs also have the authority to bill Medicare, Medicaid, commercial insurers, and, in some situations, the Veterans Administration [12]. Hence, most IHS and tribal health programs operate with a revenue stream comprised of some portion of population-based funding derived from congressional appropriations and some portion of reimbursement-based funding derived through billing of public and commercial payers. In tribal programs, these revenue streams may be supplemented to greater or lesser degrees with grant funding and tribal resources. Some 70% of Census-identified AI/AN people now live in urban areas and about a quarter of those live in an urban area served by one of 41 Urban Indian Health programs. These programs are authorized by the Title V of the Indian Health Care Improvement Act and operated by Urban Indian Organizations. While they are funded, in part, through contracts with the IHS, most Urban Indian Health programs operate as federally qualified health centers (FQHCs) with a focus on the needs of the Urban Indian population they serve and are not limited in service to IHS-eligible beneficiaries [13].

Most IHS, tribal, and Urban Indian Health programs provide primary care and public health services, including oral health (dental) and behavioral health (mental health and substance abuse) care. IHS and tribal hospitals also provide emergency services, urgent care, and some inpatient care. IHS and tribal health programs use congressionally appropriated funds and other revenue to purchase specialty care and other referral services that cannot be provided directly for eligible IHS beneficiaries [14]. Eligibility for payment for referral services is complex and rule-dependent and many IHS and tribal programs do not have adequate resources through these funds, resulting in rationed care [15, 16].

Prior to 2010, most long-term services and supports (LTSS) and all facility-based long-term care were provided outside of the authority of the IHS by tribal programs or enterprises. The permanent reauthorization of the Indian Health Care Improvement Act (IHCIA) in 2010 (a part of the Affordable Care Act) provided the IHS and tribes operating through self-governance agreements the authority to provide long-term care, home and community-based services, hospice, and assisted living, but did not include an appropriation of funds to implement these authorities. Senior centers and the tribal aging network provide elder nutrition programs, information

and referral, and some caregiver support in tribal communities, funded through Title VI of the Older Americans Act.

AI/AN Elder Demography and Social Determinants of Health

The AI/AN population is, on average, younger than the population as a whole; a smaller portion of the population is older. The median age of the AI/AN population in 2016 was 31 years in comparison to a median age for the total population as a whole of 37.9 years [17]. In 2017, only 10.3% of the Census estimated AI/AN population was 65 years old or older, compared to 15.6% of the total population. The proportion of the population older than 75 (3.2%) was only half that of the total population (6.5%) [17]. The older AI/AN population is however, growing more rapidly than the older US population. The number of individuals reporting as American Indians and Alaska Natives alone is projected to increase from 266,000 in 2012 to 996,000 in 2050, increasing from 0.1% of the US population in 2012 to 0.3% of the total population in 2050 [18].

AI/AN elders are more commonly caregivers and also more commonly live alone. Compared to the same-aged general US population, almost double the percentage of AI/AN elders have grandchildren in their homes (10 percent vs 5.4) and provide care for them (4.8 percent vs 2). At the same time, more AI/AN elders live alone compared with the same-aged group in the US population [19••].

On a variety of indicators, AI/AN elders have less wealth, lower income, and higher rates of poverty than US elders as a whole. Fewer AI/AN elders are employed and this disparity is most marked in the cohort aged 50–64. For AI/AN ages 50 and over, the mean yearly income is about 75% of that of the general population of the same age. Nearly twice as many AI/AN elders are uninsured compared to people of the same age in the US population [19••]. 17.5% of AI/AN age 50 and older live in poverty, compared to 9.5% of the general population of the same age [19••]. Nearly a quarter (24.8%) of AI/AN age 50 years and older have a college degree of an Associate's Degree or higher, compared to nearly a third of the same-aged US population (32.7%) [19••].

These disparities in older American Indians and Alaska Natives reflect significant wealth and income disparities in the AI/AN population as a whole. The unemployment rate among AI/ANs nationally (10.2%) is nearly twice that of the total population (5.3%) [20]. 34% of AI/AN households in tribal areas had one or more physical problems (plumbing or kitchen deficiencies, heating or electrical problems, or overcrowding), compared to only 7% for US households [21].

AI/AN Elder Health Status Through the Lens of Health Disparities

We can gain an understanding of health status and health disparities of AI/AN elders through viewing the relatively limited elder-specific data in the context of the broader AI/AN population and by integrating the knowledge gathered from population-based studies with research on smaller and more specific tribal or community cohorts.

AI/AN born today have a life expectancy that is 5.5 years less than the US all races population (73.0 to 78.5 years, respectively). Much of this decrease in overall life expectancy is due to higher death rates at younger age, seen especially in disparate mortality from suicide, homicide, and unintentional injuries and from higher infant mortality rates. In 2007–2009, 25% of AI/AN deaths were in individuals under the age of 45, compared to 8% in US all races. In the age cohorts between 45 and 64 years, there is, in addition, an increasing contribution to mortality disparity from heart disease, cancer, diabetes, and liver disease [22]. Death rates are significantly higher for AI/AN than for US all races in all cohorts except those aged 75 and older and higher than white Americans at all ages, although regional differences occur; AI/AN elders aged 85 and older have similar or lower death rates than white elders of the same age in the Southwest, Pacific Coast, and Eastern USA [23••]. Importantly, all-cause death rates in the AI/AN population did not show the decline seen in the US population as a whole during the period from 1990 to 2009 [23••].

For AI/AN age 65 and older during the period 2009–2011, heart disease, cancer, diabetes, chronic liver disease, and stroke are the leading causes of deaths [22]. The largest contributor to chronic liver disease is alcoholic cirrhosis, but AI/AN elders also have higher rates of hepatitis B and C than older white individuals [23••]. Mortality data available through the IHS suggests a death rate from Alzheimer's disease that is half that of the US all races but there are reasons to doubt that this reflects true population burden [22]. These include likelihood of under-diagnosis of dementia in this population, misclassification of American Indian or Alaska Native status on death certificates, and under-reporting of dementia on death certificates in the general population [24–26]. In fact, recent studies suggest a rate of dementia similar to US all races among a large insured self-identified AI/AN population in Northern California and higher than non-indigenous populations among the First Nations of Alberta, Canada [27••, 28].

In aggregate survey data from 2011–2014 of AIAN elders age 55 and older from 262 federally recognized tribes receiving the Title VI Nutrition and Caregiving Grant administered by the Administration for Community Living (ACL) of the US Department of Health and Human Services, 89.7% of elders had been diagnosed with at least one of 10 chronic diseases. Low-income elders were 1.3 times more likely to

be diagnosed with one or more chronic conditions than high income elders [29].

In the 2000 Census, AI/AN elders reported more functional, mobility, and self-care disability (correlating to basic and instrumental activities of daily living) than white respondents. In a more recent survey of Medicare Managed Care enrollees, AI/ANs reported rates of impairment in activities of daily living that were among the highest of all racial and ethnic groups [30].

Fall-related injury is a significant cause of morbidity and mortality and older AI/ANs aged 65–74 have increased mortality due to fall when compared to whites of the same age [31]. Anecdotal evidence is emerging of an increased risk to elders resulting from the current epidemic of opioid use, including increases in theft of prescription medications and in elder exploitation and neglect.

Improving the Health Status of AI/AN Elders

Strategic efforts in clinical care, public health interventions, and long-term services and supports will be necessary to improve the health status of AI/AN elders. These efforts must make full use of the health care and tribal or community resources available, and build on strengths and capabilities in the culture. This cultural capital includes the traditional knowledge and core values tribes retain and use in education, incorporating social history. These important resources have demonstrated value in promoting health/wellness and disease prevention [8].

Clinical Care

Improvement in the clinical care of the AI/AN elders should be focused on increasing the capability of primary care in the tribal, IHS, and Urban Indian Health programs to manage a population with multiple comorbidities and the syndromes of aging.

Structured decision support for diagnosis and management in the common and important health conditions of the elderly, especially dementia and falls. Effective interventions include integration of algorithms and templates in the electronic health record and increased access to specialty consultation using telehealth modalities.

Targeted care management, embedded in the primary care team, supports elders at highest risk to navigate the complexity of their chronic conditions and of the health system. The elders' values and wishes should guide the goals of care management and advanced care planning.

Regular, periodic, and comprehensive medication review aimed at reducing polypharmacy and the use of medications in which risks outweigh potential benefits for the elderly. This strategy would leverage the strong clinical pharmacy programs available in many Indian healthcare programs.

The capability to provide care at the end of life that is responsive to the wishes of the elder and their family requires competency in palliative care clinical skills, including facility in the conversations necessary to understand the elder's care preferences. These skills must be informed and guided by knowledge from within the culture.

Implementation of a periodic comprehensive assessment for all elders provides an opportunity for comprehensive medication review, screening for fall risk, assessment of cognitive function, preventive care, and the crucial conversations that inform care that conforms to the elder's care values and care preferences. The Medicare Annual Wellness Exam is a good model for this process. This assessment should leverage the unique resources available in tribal and Urban Indian communities, including public health or community health nursing, community health representatives and other paraprofessionals, community-based diabetes prevention and wellness initiatives, and, of course, senior centers and other tribal aging services.

Public Health Interventions

Public health efforts to address habitual tobacco use and alcohol misuse are established in most tribal communities; these efforts should include attention to older individuals. A comprehensive approach to fall and injury prevention would integrate community-based interventions such as exercise, education, and home safety assessment with clinical interventions such as a multi-disciplinary assessment and targeted intervention for elders at increased risk for falls [32].

Long-Term Services and Supports

There is a well-documented paucity of formal programs and service for AI/AN elders and their families with need for assistance in activities of daily living [33]. We can look to existing tribal programs for models and to AI/AN elders for guidance.

Tribes and Urban Indian organizations should be the focus of efforts to develop long-term services and supports for AI/AN elders. This is most likely to ensure that the services developed are supported by and consistent with tribal culture and responsive to the preferences of the elders.

Evidence-based caregiver support services for elders with dementia and frailty are an essential component of home and community-based services. Care for the elder with dementia should include care for the caregiver. Educational interventions such as the Savvy Caregiver have been adapted for tribal communities and an intervention adapted from the NIA-funded REACH trial have been implemented in a number of tribal communities [34, 35].

Access to a comprehensive set of long-term services and supports in tribal communities will be incomplete and progress in their development will be highly variable until there is a dedicated funding stream for the investments necessary to implement these services.

Data to Guide Improvement in Health Status

The relative paucity of data specific to the health status of AI/AN elders, their access to care and services, and the impact of interventions has the potential to undermine the effectiveness of our actions. Age-specific surveillance and epidemiologic data will facilitate strategic allocation of resources. Demonstrations of intervention effectiveness in AI/AN elders will aid in the spread of these interventions. Improved data regarding function, quality of life, and the elders' experience of care will provide a basis for assessing progress in efforts to improve population health status as well as the quality of care and services. This data is necessary to guide improvement at national and tribal levels and for Urban Indian communities.

Importantly, major impact on elder health status can only come through improvement in injury rates and chronic disease burden for American Indians and Alaska Natives in youth and middle age [22]. Recent experience in reducing rates of diabetes-related end-stage kidney disease demonstrate the ability of IHS, tribal, and Urban Indian health programs to impact on chronic disease burden [36•]. Resources necessary to improve elder health status must not come at the expense of care and services for younger American Indians and Alaska Natives.

Table 1 contains a short set of high leverage strategies for improving AI/AN elder health that build on the strengths and assets of the Indian Health system and are feasible within existing resources.

Table 1 High leverage strategies for improving AI/AN elder health

High leverage strategies that can be initiated within existing resources:

1. Reduce the risk of fall-related injuries through implementation of routine screening for fall risk, multi-disciplinary assessment, and targeted interventions for both the individual elder and their environment to reduce fall risk.
2. Ensure access to evidence-based caregiver support for elders with dementia and frailty in every tribal and Urban Indian community provided through the tribal aging network, public and community health nursing programs, and community health representatives.
3. Develop decision support tools and training resources for the diagnosis, assessment, and management of Alzheimer's disease and related dementias.
4. Integrate care management into primary care services, targeted to elders and younger adults with frailty, dementia, complex comorbidities, and in transitions of care.
5. Routinely offer an annual comprehensive exam for elders. This can start with older cohorts of elders and move younger as resources allow.

Conclusion

Older American Indians and Alaska Natives carry a significant burden of chronic disease and disability. Addressing social determinant of health and the resource limitations within the Indian health system are critical in efforts to improve health status. A targeted set of high leverage strategies addressing clinical care, public health, and long-term services and supports can improve the health status of current and future elders and we are reliant on elder-specific data at the national and tribal level to understand the impact and effectiveness of these interventions. These efforts will only be successful if they are built into and on the foundation of strengths, resources, and cultural capital present in tribal communities. Ultimately, the path to healthier AI/AN elders in the future is through investing resources to ensure that this population is healthier across the lifespan.

Compliance with Ethical Standards

Conflict of Interest Bruce Finke and Blythe Winchester each declare no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Disclaimer The opinions expressed in this paper are those of the author(s) and do not necessarily reflect the views of the IHS.

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