

Introduction

Data Gaps in American Indian/Alaska Native Research

- Prior research suggests that there are issues with data collection, estimation, and power regarding American Indian/Alaska Native public health studies (Moy et al., 2006)

Neuropsychology

- The American Psychological Association describes Neuropsychology as the branch of science that studies the physiological processes of the nervous system and relates them to behavior and cognition, in terms both of their normal function and of the dysfunctional processes associated with brain damage (APA, 2023)
- The American Academy of Clinical Neuropsychology (AACN) has announced a “Relevance 2050 Initiative” that seeks to recruit more neuropsychologists from diverse linguistic, cultural, socioeconomic, and religious backgrounds. (AACN, 2023)

Arachnoid Cysts

- Arachnoid cysts are classified by the National Institute of Health’s Genetic and Rare Diseases Information Center as sacs filled with cerebrospinal fluid (CSF) that are located between the brain or spinal cord and the arachnoid membrane (GARD, 2023)
- Some of the symptoms reported of having arachnoid or intracranial cysts are: abdominal pain, cranial nerve paralysis, back pain, abdominal pain, headache, depression, diminished motivation, hemiparesis, and hydrocephalus (GARD, 2023)
- The etiology of these cysts is largely unknown and there is a large gap in the literature in this as well as in symptomology and presentation of the neurodevelopmental disorder

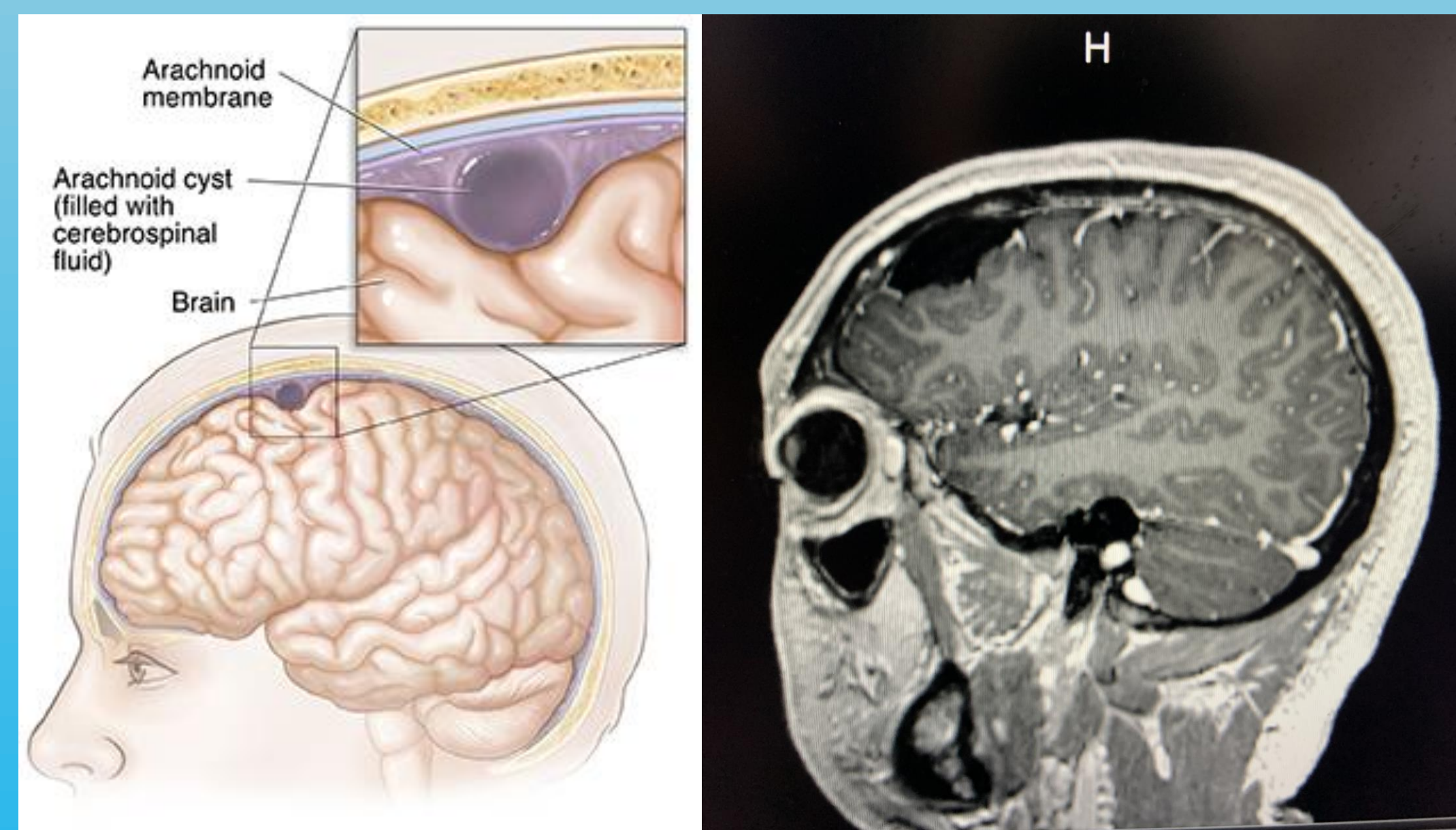


Figure 1: An illustration depicting an arachnoid cyst in the brain (left), and a T2 Weighted Flair Brain MRI (Sagittal) with an arachnoid cyst located in the right anterior lobe (right).

Where are we at?

Data Collection

- Participants in the arachnoid cyst studies were mostly recruited with symptomology of anterior or temporal cyst. Others were recruited that were awaiting surgery for arachnoid cysts
- Most of the samples were from European countries and very little were observed in a research setting in the United States
- Cognitive testing was administered by a Neuropsychologist for the studies measuring cognition (Delis-Kaplan Executive Function System or D-KEFS)
- Data gaps were determined via data review and statistical analysis validity review

Why is this a Tribal Public Health issue?

Mistrust in Medicine

- Events such as Arizona State University’s mistreatment of the Havasupai Tribe’s data further perpetuate AI/AN mistrust of researchers in medicine (Garrison, 2013)
- In terms of satisfaction with healthcare, AI/AN have been shown to have a lower satisfaction and higher mistrust than white individuals in cancer treatment studies (Guadagnolo, 2009)
- There is evidence from early studies that normative data for AI/AN people may overestimate their neurocognitive impairment (Savin, 2020)

Health Disparities in American Indian/Alaska Native Populations

- American Indian/Alaska Native (AI/AN) peoples experience a disproportionate disparity in healthcare and part of that disparity is the lack of cultural competency/humility amongst healthcare providers
- According to the Center for Disease Control’s Behavioral Risk Factor Surveillance System (BRFSS) Survey, AI/AN in Arizona had a lower prevalence of having a personal doctor or health care provider (Adakai et al., 2018)
- The life expectancy for AI/AN peoples is also the lowest on average in the United States (Arias et al., 2019)

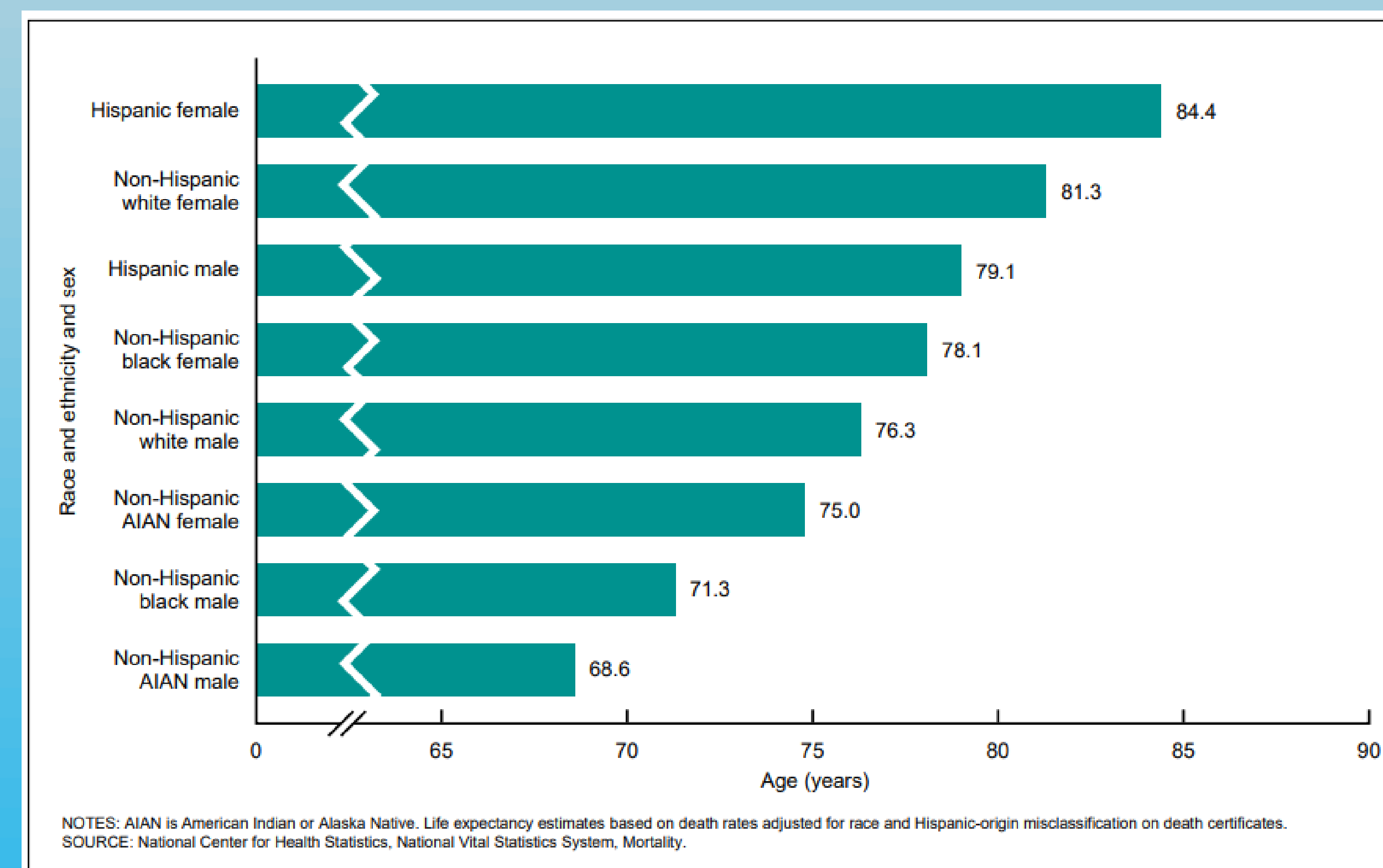


Figure 2: A graphic comparing life expectancies of different populations based on race/ethnicity. (Reprinted from: “Mortality Profile of the Non-Hispanic American Indian or Alaska Native Population, 2019”)

Where can we go from here?

Future Data Collection

- More research in arachnoid cysts in the U.S. generally as well as with AI/AN peoples is required
- Neuropsychological assessment can assist in diagnostic processes for cysts as well as comorbid conditions

Cultural Competency/Humility

- The term cultural competence refers to the means of attending to the culturally diverse backgrounds of patients, providing person-centered care, and reducing health disparities. (Lekas, 2020)
- Cultural humility refers to the understanding of one’s own cultural background and willingness to learn about other cultures (Lekas, 2020)

How can health equity be achieved?

Consider the History of AI/AN Peoples

- AI/AN people are survivors of mass genocide and repeated attempts of extermination. With this knowledge comes the responsibility of clinicians and researchers to acknowledge their own history and take that all into very careful consideration when working with AI/AN people

Holistic Healthcare Systems

- The whole self should be considered when a patient is undergoing treatment as other factors that are not typically considered can negatively impact one’s health

Collaborative Partners vs. Study Subjects

- Tribes should be collaborated with, and their sovereignty as a nation respected when research is done with them

Treat the Person, Not the Condition

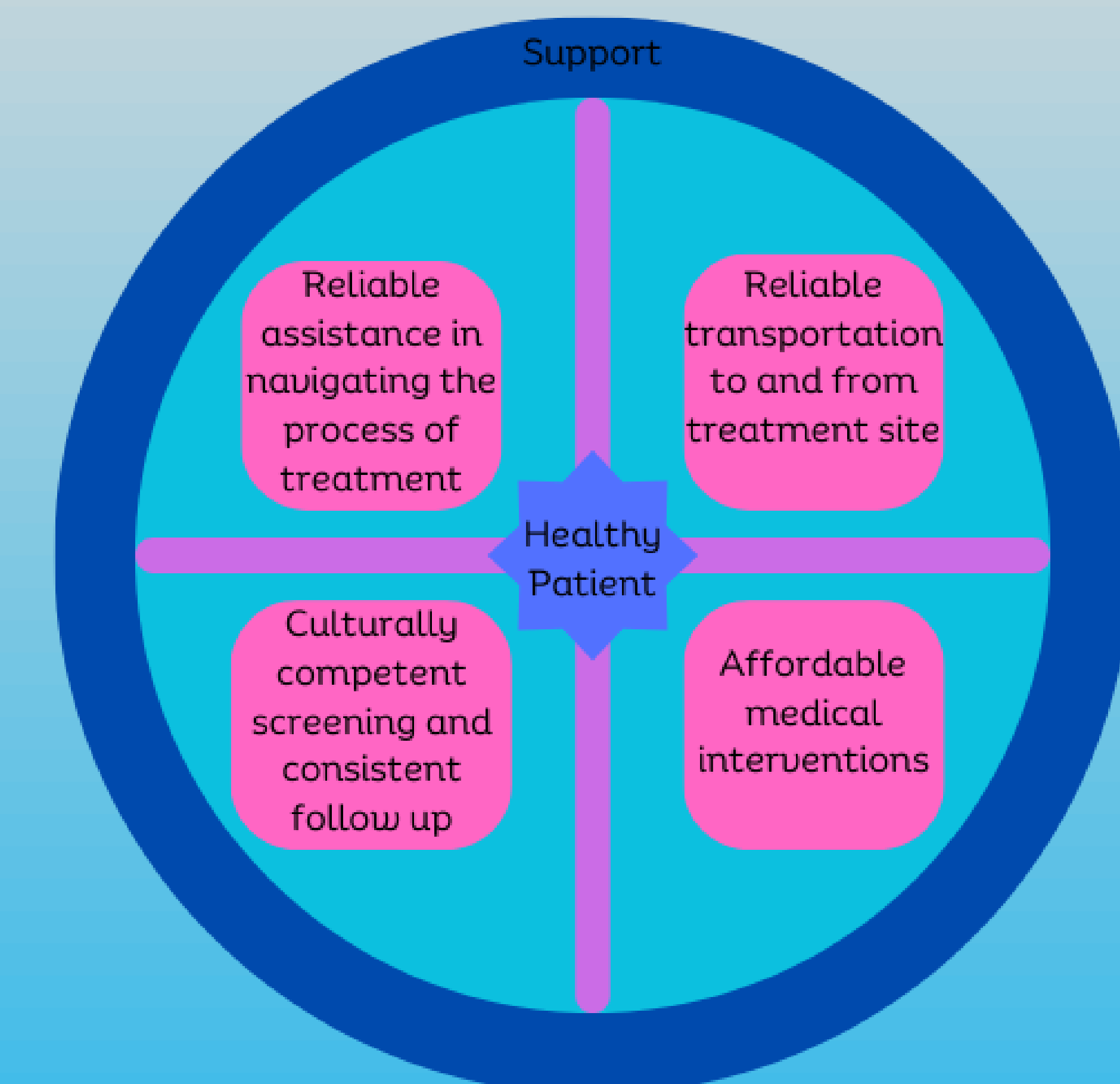


Figure 3: A medicine wheel graphic depicting four components to having a healthy patient.

Takeaway messages

Increase Culturally Conscious Practices with AI/AN Peoples

- Arachnoid cyst prevalence is not well known even in the general population which creates an issue for AI/AN prevalence statistics due to the already existing health disparities AI/AN people face

Rare Does Not Mean Nonexistent

- Though the prevalence of arachnoid cysts is largely unknown in the United States, it is therein that the danger lies

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