SUSTAINABILITY AND DISABILITY: CYSTIC FIBROSIS AND INDIGENOUS PEOPLE

DESIGNING STRATEGIES AND POLICIES TO ADDRESS DISABILITY ISSUES IN INDIGENOUS COMMUNITIES

SUDI CONFERENCE MARCH 2-3, 2017 ISLETA RESORT AND CASINO

MY INSPIRATION: MALICI SEWA AND WAMBLI WAH-WALA

As a scholar and researcher I would have not been so involved with Cystic Fibrosis had it not touched the life of my daughter and grandson, they are the core of my being. (Malici's full interview appears in the publication.)

INDIGENOUS WORLD VIEWS

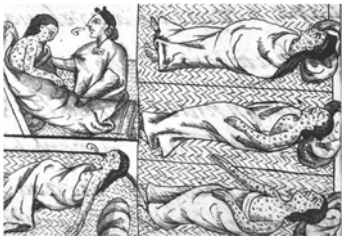
Addressing Cystic Fibrosis including other diseases where little is known in the native community is a traumatic experience. In the past, oral accounts of certain diseases: small pox, chicken pox, influenza were passed down from generation to generation and served as disease history. Currently, more data is needed to identify specific genetic mutations to individually treat a baby or person with Cystic Fibrosis.

Historically, imbalances and a broad range of health conditions were the domain of native community healers. In the past, the emotional, psychological, physical and spiritual aspects of the infirmed and the family were given support and attention directed through prayer thus the psychological aspect and the importance to healing was exemplified.

Part of our task today in regard to developing strategies and policies for asymptomatic diseases is to inform the health care givers on how disease was approached in the past.

SOME IMAGES THAT SERVE AS PART OF DISEASE HISTORIES

MORTAL SICKNESS AMONG THE INDIANS.



Smallpox Symptoms (Black-pox)

CONCERNS: MORE DATA NEEDED

- NATIVE AMERICANS AND THEIR HEALTH CARE PROVIDERS COULD BENEFIT BY KNOWING THE YEAR WHEN NATIVE AMERICAN GENOTYPING WAS INTRODUCED AND ESTABLISHED, INCLUDING WHEN SPECIFIC MUTATIONS APPEARED AND THE SUBSEQUENT YEARS OF CF PRESENCE ALL THE WAY UP TO THE PRESENT DAY THAT SHOW THE INCREASE OF IDENTIFIED CF NATIVE AMERICANS.
- THEIR NUMBERS AND THEIR OCCURRENCE IN SPECIFIC NATIVE AMERICAN POPULATIONS AND COMMUNITIES WILL HAVE A DIRECT EFFECT ON RECOMMENDATIONS FOR SERVICE PROVIDERS AND POLICY MAKING THAT IS UNIQUE TO NATIVE COMMUNITIES ON HOW BEST TO SERVE THEM. FOR EXAMPLE; LOCATION, ISOLATION, DISTANCE TO HEALTHCARE FACILITIES, ACCESS TO HEALTHCARE FACILITIES, KNOWLEDGE REGARDING CF, TRANSPORTATION AND AFFORDABILITY TO ADEQUATELY AND MEDICALLY ADDRESS THE DEMANDS OF CARING FOR AN INFANT OR PERSON WITH CF.
- ALSO, IT MAY BE BENEFICIAL TO KNOW THE DISTRIBUTION OF CF BY NUMBERS AMONG ALL OF THE TRIBAL NATIONS, AND IF, WHEN, AND WHERE CF HAS HAD A SIGNIFICANT GROWTH. MOST STATISTICAL DATA CAN PROVIDE GENERAL INFORMATION ABOUT HOW COMMON A CONDITION IS, AND HOW MANY PEOPLE HAVE THE CONDITION.

WHO HAS CYSTIC FIBROSIS?

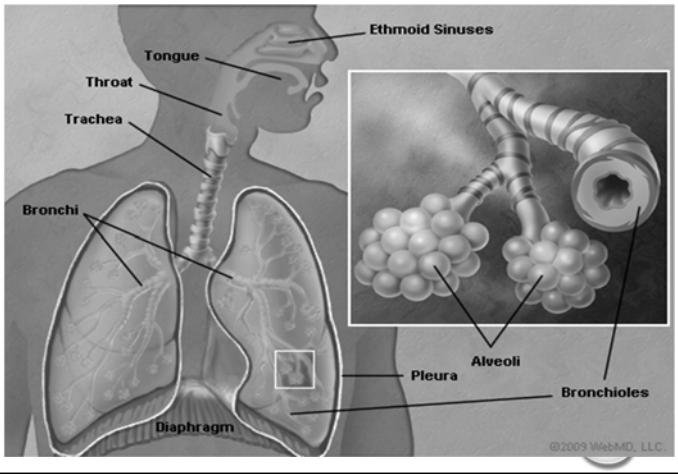
- WHO HAS IT?
- ABOUT 1 OUT OF 2,500 LIVE BIRTHS IN THE CAUCASIAN RACE ARE DIAGNOSED WITH CYSTIC FIBROSIS, 1 OUT OF 10,900 IN AMERICAN INDIANS, 1 OUT OF 15,000 BLACKS, 1 OUT OF 35,000 ASIAN. ACCORDING TO ELSEVIER PUBLISHING, (2015), CYSTIC FIBROSIS OCCURS LESS FREQUENTLY IN NONWHITE THAN IN WHITE, AND NONWHITE TEND TO BE DIAGNOSED AT A LATER AGE.
- A NEW STUDY IN THE JOURNAL OF MOLECULAR DIAGNOSTICS, (2016) FOUND THAT ONE REASON FOR THIS ETHNIC DISPARITY IN CF DIAGNOSIS IS THAT VARIANTS EXAMINED IN THE MOST COMMON CF NEWBORN SCREENING PANELS DO NOT SUFFICIENTLY INCLUDE THE VARIANTS IN NONWHITE POPULATIONS.
- THIS STATEMENT DOES NOT HOLD ENTIRELY, THE RESEARCHERS FOUND THAT 90% OF WHITE PATIENTS AND 83% OF NATIVE AMERICANS WITH CF HAVE A PARTICULAR MUTATION (P.PHE508DEL), AND ABOUT HALF OF THESE INDIVIDUALS HAVE TWO COPIES OF THESE MUTATIONS. THEY ALSO FOUND THAT 30% OF HISPANICS, 38% OF BLACKS, AND 41% OF ASIANS DID NOT EVEN HAVE ONE COPY OF THE MUTATION.

WHAT IS IT?

- AMONG THE MULTIPLE DEFINITIONS FOR CYSTIC FIBROSIS MOST HOLD THAT CF IS AN INHERITED DISORDER, AND AFFECTS THE EXOCRINE EPITHELIAL CELLS OF MULTIPLE TISSUES AND ORGANS.
- SERIOUS PULMONARY PROBLEMS MANIFEST OVER TIME, INCLUDING CHRONIC LUNG INFECTIONS, AND AIRWAY INFLAMMATION. OTHER SYMPTOMS INCLUDE FAILURE TO THRIVE, PANCREATIC INSUFFICIENCY, INFERTILITY, AND BOWEL OBSTRUCTION. EACH PERSON WITH CF WILL EXPERIENCE THESE SYMPTOMS AND OTHER CONDITIONS UNIQUELY, SOME OF THE MANIFESTATIONS ARE DETERMINED BY SEVERITY AND ONSET AND MOST CULMINATE IN THE ADULT STAGES OF LIFE.

SACRED ELEMENTS AMONG INDIGENOUS PEOPLES:
EARTH, WATER, AIR-WIND-BREATH, AND FIRE

THE LUNGS ARE THE KEEPERS OF AIR-WIND-BREATH



LAND BASED DNA FROM AN INDIGENOUS PERSPECTIVE

- EVEN WITH THE CURRENT PERCENTAGES OF NATIVE PEOPLES IDENTIFIED WITH CF THERE IS STILL RELATIVELY LITTLE INFORMATION ABOUT NATIVE PEOPLE IN RELATIONSHIP TO MOST STUDIES ON CF. PERHAPS, VIEWING DNA AND GENETIC INFORMATION FROM ANOTHER ANGLE MAY PROVIDE OBSCURE INFORMATION REGARDING THE SIMILARITIES FOUND IN GEOGRAPHICAL DNA TO INDIGENOUS-NATIVE DNA.
- IF WE LOOK AT THE WORK BY KIM TALL BEAR IN HER BOOK NATIVE AMERICAN DNA, (2013), WE FIND THAT THERE ARE MANY SCIENTIFIC ASSUMPTIONS REGARDING THE ORIGINS OF INDIGENOUS DNA AND BIOREGIONS. TALL BEAR STATES, "BIOGRAPHIC ORIGINS MUST BE ASSUMED IN ORDER TO CONSTITUTE THE DATA THAT SUPPOSEDLY REVEALS THOSE SAME ORIGINS. NATIVE AMERICAN DNA AS AN OBJECT COULD NOT EXIST WITHOUT, AND YET FUNCTIONS AS A SCIENTIFIC DATA POINT TO SUPPORT THE IDEA OF, ONCE PURE, ORIGINAL POPULATIONS."
- PERHAPS, WHAT WE (RESEARCHERS) SHOULD BE LOOKING FOR ARE THE DNA SIMILARITIES FOUND IN THE SOIL AND WATER OF A PARTICULAR BIOREGION IN RELATIONSHIP TO THE INDIGENOUS POPULATION FROM THAT SAME BIOREGION. FROM A FUNDAMENTAL POINT WE COULD THEN ADDRESS THE ANCESTRAL ORIGIN OF THE MUTATION AND POSSIBLY IDENTIFY UNIQUE INDIGENOUS VARIANTS.

WHEN WORKING WITH INDIGENOUS POPULATIONS THE ORIGIN AND CAUSE AND EFFECT ARE NECESSARY FOR TRADITIONAL (NATIVE) HEALING

- STRATEGIES:
- Create an Native American Cystic Fibrosis Data Base by region.
- Create nanny-home care-babysitter referral list by community.
- Encourage parents to become recipients of a Cystic Fibrosis Newsletter.
- Keep parents informed about on-going approved clinical trials and new treatments
- Native spiritual limitation should be addressed by all service providers; thus providers need to be culturally responsive.

WE HAVE COME TO A TIME WHERE HEALTHCARE PROVIDERS MUST BE INCLUDED IN THE NATIVE PRAYER AND CEREMONY TO THE POINT WHERE IT IS (NATIVE) CULTURALLY ACCEPTABLE

- POLICIES:
- Cystic Fibrosis research must be conducted to include all diverse indigenous peoples (US) in their findings in order to acquire adequate knowledge of the various mutations (most and least common).
- Healthcare providers must have an understanding of the native experiences (both on and off the reservations), and the family's decision-making processes that involve their CF family member.
- Healthcare providers of native CF patients must know they are not just treating an individual, they are treating the entire family.
- Healthcare providers must be prepared to discuss the needs of western science to native people including the importance of testing, research, data, and potential outcomes.
- Health care providers must respect and be prepared to have CF individuals who do not accept the invasiveness of western medicine and look for other ways to work with those individuals, however limited.

BIBLIOGRAPHY

- Casteel, Malici Sewa, 2017 (image)
- Journal of Molecular Diagnostics, 2016
- Lung and Respiratory Health Center, 2014, WebMD, LLC, Image Collection: Human Anatomy