3D LUNG VOLUME CALCULATION FOR SCOLIOSIS

BARRIERS TO HEALTHCARE FOR THE MARSHALLESE IN NORTHWEST ARKANSAS

An Undergraduate Thesis Portfolio
Presented to the Faculty of the
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In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science in Biomedical Engineering

By

Sam Schach

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BARRIERS TO HEALTHCARE FOR THE MARSHALLESE IN NORTHWEST ARKANSAS

A Research Paper submitted to the Department of Engineering and Society
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March 25, 2021

On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

Signed: Sam Schach Date: March 24, 2021

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Some groups have fallen between the cracks in the US health care system. Often these groups face unique barriers to treatment, and the standard of care and health care infrastructure are not created with these groups in mind. Physicians are often put in a difficult situation when they are determining the proper standard of care for early onset scoliosis (EOS) patients. A common surgical option is spinal fusion, which corrects the spinal deformity and curvature seen in scoliosis patients. An incision is made in the patient's back and their muscles are moved away so that the spine is exposed (Spinal Fusion for the Treatment of Idiopathic Scoliosis in Children, 2009). As seen in Figure 1, two metal rods are then placed alongside the vertebrae forcing it to straighten. In order to determine if spinal fusion surgery should be performed, accurate measurements of the patient's total lung capacity (TLC) are needed. If spinal fusion surgery is performed before the lungs have sufficiently developed, then patients can develop restrictive pulmonary disease. Two common methods for measuring TLC are spirometry or pulmonary function testing, and computed tomography (CT)(Delgado & Bajaj, 2020). However, there are drawbacks to these methods that are more prominent with EOS patients. It is difficult for young children or those experiencing disability to perform the pulmonary function test properly, due to the specific commands that have to be followed during the test, and CT scans subject patients to also roughly 300 times the amount of radiation of an X-ray (Mettler et al., 2008, p. 356)

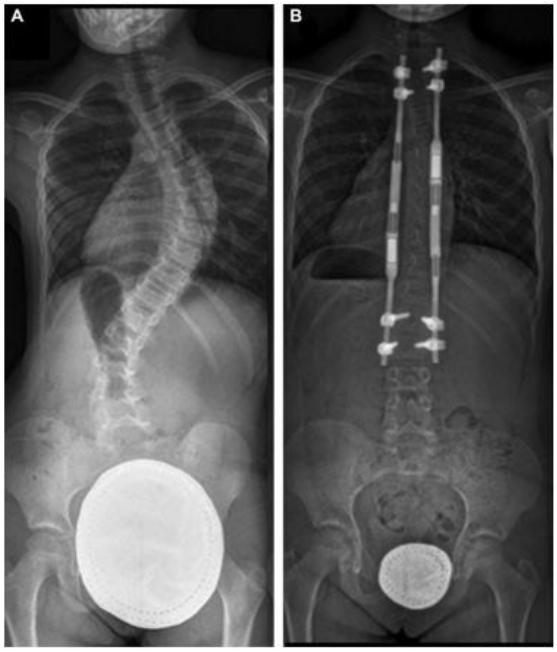

Figure 1: Spinal Fusion X-rays. A shows an X-ray before spinal fusion and B shows the results of spinal fusion surgery (Beauchamp et al., 2019, p. 299).

Currently, some patients with EOS have trouble complying with the current methods of measuring lung volume. These patients are either too young or may be disabled, as the large majority of neuromuscular scoliosis cases are associated with cerebral palsy (Murphy & Mooney, 2019, p. 225). X-ray images are already taken to monitor the progression of EOS. Therefore, if these images are used the patient would not be subjected to additional costs or radiation. Using X-ray images will provide a novel method for calculating TLC and allow physicians to better serve young children and those experiencing disability.

The STS research is loosely coupled to the technical project as it also focuses on an underserved population. The Marshallese community in Northwest Arkansas has been disproportionately affected by tuberculosis and more recently Covid-19 (McElfish, 2021; Rothfeldt, 2016). Washington County, Arkansas is home to the largest population of Marshallese islanders in the continental United States (Pearl A. McElfish et al., 2019, p. 3). Pacific islanders, including the Marshallese, are estimated to make up 2.8% of Washington County's population (U.S. Census Bureau QuickFacts, n.d.). Although the Marshallese account for a very small amount of the population, they make up 79% of all tuberculosis cases in Washington County in a 2016 study (Rothfeldt, 2016). Five years later, the Marshallese in Northwest Arkansas were disproportionately affected by another outbreak. McElfish (2021) found that the Marshallese made up 19% of Covid-19 cases in the region. There was an even greater disparity when deaths due to Covid-19 are examined. They accounted for 38% of Covid-19 deaths in Northwest Arkansas (Center et al., 2020). This is likely due to a combination of factors including high rates of type 2 diabetes in the Marshallese population and poor access to healthcare coverage (Pearl Anna McElfish, Hallgren, et al., 2016; Pearl Anna McElfish et al., 2017). McElfish (2017) found that 46% of Marshallese adults in Arkansas have type 2 diabetes which increases the risk of

severe illness from Covid-19. When the Marshallese were surveyed, they were very aware of the dangers of type 2 diabetes but were ill-informed on the benefits of diabetes self-management (Pearl Anna McElfish, Hallgren, et al., 2016).

A lack of healthcare coverage is a major barrier that stops many of the Marshallese from getting sufficient health care or tuberculosis treatment. A survey of the 394 Marshallese in Northwest Arkansas found that 46% did not have any health care coverage (McElfish et al., 2017). Many Marshallese are uncomfortable speaking English in a clinical setting and some medical terms have no direct translation into Marshallese (Williams & Hampton, 2005, p. 323). Marshallese were interviewed in focus groups organized by Ayers et al. (2019) and they vocalized the challenges they faced due to the language barrier: "We might know how to speak English, but the medical terms being used to explain the conditions by the doctors is like a puzzle waiting to be solved, but we are afraid to ask what the meaning of their terms are" (p. 150). Both the complex medical language and the Marshallese's unease around doctors makes it difficult to foster trust and a strong doctor-patient relationship so that treatment can be effectively administered.

The goal of this paper is to determine why the Marshallese are more susceptible to outbreaks like Tuberculosis and to determine how best to enroll the Marshallese in Medicaid. This paper will focus on working within the local community to help educate the Marshallese on the benefits of Medicaid and provide guidance on enrollment.

AN ACTOR NETWORK APPROACH TO INCREASING HEALTHCARE UTILIZATION AMONGST THE MARSHALLESE POPULATION

This paper will examine healthcare disparities in the Marshallese community through the use of Actor Network Theory (ANT). ANT is centered on relationships between actors and

actants (Law & Callon, 1988. p. 285). As seen in Figure 2, the primary actors in this paper are the Marshallese population of Northwest Arkansas (NWA), local health care system, and Marshallese community groups.

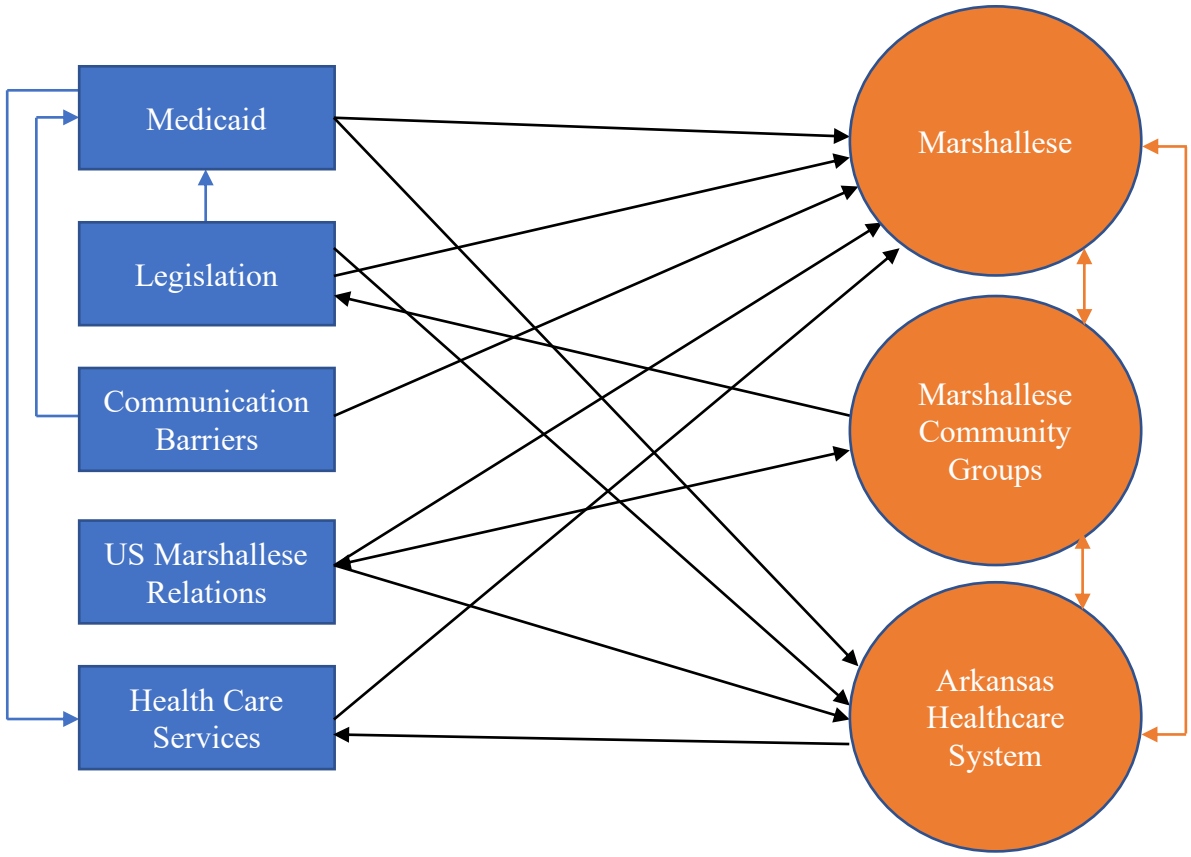

Figure 2: Actor Network Theory Applied to the Marshallese's Barriers in the Healthcare System. The blue rectangles represent actants, and the orange circles represent the actors. Blue lines represent the impact actions of actants have on other actants. Black lines represent impacts between actants and actors, and orange lines represent interactions between actors (Schach,2021).

Within this network the relationship between the Marshallese and the Arkansas Health Care system may be the most lacking. The Marshallese are not well informed on the benefits of health insurance, preventative care, or the proper way of making appointments and follow ups (McElfish et al., 2020, p. 8; Williams & Hampton, 2005, p. 322). McElfish et al. (2020) surveyed physicians that served the Marshallese population and observed that the "Marshallese access the health care system through the emergency room" (p.8). This survey also found that many clinics

do not have access to translation services and online services like Google Translate do not support the Marshallese language. This makes it very difficult for receptionists to schedule appointments and follow ups (McElfish et al., 2020, p. 7). This leads to long wait times at the clinic which can further discourage them from seeking preventative care. Many local physicians sympathize with the Marshallese but lack both the resources and the monetary incentive to provide better care.

THE IMPACT OF NUCLEAR TESTING AND SUBSEQUENT WESTERNIZATION ON THE REPUBLIC OF THE MARSHALL ISLANDS

As seen in Figure 2, US Marshallese relations affect all the actors in the network. In order to understand why this, their history must be explored. From 1946 to 1958 the US detonated over 50 nuclear weapons over the Republic of the Marshall Islands (RMI) (Brown, 2014). The US failed to educate the Marshallese on the dangers of nuclear fallout, and when ash began raining down from the sky, children tasted it and women used the ash as shampoo (Schwartz, 2012).

The United States saw the RMI as a strategic position and a prime location for missile and interceptor testing (*Reagan Test Site | MIT Lincoln Laboratory*, n.d.). This led to the creation of the Reagan Test Site on the largest island in the Kwajalein atoll and the displacement of its Marshallese residents (Yamada & Palafox, 2001, p. 703). Nuclear testing, relocation, and the creation of the Reagan Test site led to rapid westernization in the RMI. Traditionally, the Marshallese would often work in agriculture, gather food on the surrounding reefs, and "traditional staple foods… were taro and breadfruit", but after US occupation, lifestyles became more sedentary and traditional staple foods were replaced with imported white rice and processed foods (Yamada & Palafox, 2001, p. 703).

Rapid westernization resulted in an increase in non-communicable disease in the RMI. In

the 1950's there were only three known cases of diabetes in the entire country, but in the 1990's the prevalence of diabetes reached 30% (Davis et al., 2019). This increase in diabetes stems from the change in diet that led to 62% of the residents aged 15-64 being either overweight or obese (Ichiho et al., 2013). The high prevalence of non-communicable diseases within the Marshallese community makes them more susceptible to illness. Tuberculosis becomes an even more serious health threat for diabetics because it increases the chances that the tuberculosis infection will not be latent or quickly progress past the latent stage.

THE RMI AND THE COMPACT OF FREE ASSOCIATION

In 1986, well after nuclear testing was completed, the RMI "became ostensibly sovereign" and entered a Compact of Free Association (COFA) with the United States (Pearl A. McElfish et al., 2019).When the COFA was signed, the Marshallese were eligible for federal benefits such as Medicaid (Pearl Anna McElfish et al., 2016, p . 2). However, in 1996 the Personal Responsibility and Work Opportunity Reconciliation Act was passed and COFA migrants lost their Medicaid eligibility (*Korab v. Fink*, 2012, p. 2; Pearl Anna McElfish et al., 2016, p . 2). They remained ineligible until December 21, 2020 when the Covid-19 relief bill was passed, and COFA migrants had their Medicaid eligibility reinstated (House passes COVID-relief and spending package, includes several Cárdenas priorities | U.S. Congressman Tony Cárdenas, 2020). Taking away Medicaid eligibility, nuclear testing, and subsequent studies carried out on the Marshallese without their consent under the guise of treatment created the foundations of distrust between the Marshallese and the US healthcare system (Brown, 2014). Marshallese community groups are working to establish trust and systemic change by providing education and an avenue for legislative change for the Marshallese.

MARSHALLESE COMMUNITY GROUPS

In 2015, Melisa Laelan founded the Arkansas Coalition of Marshallese (ACOM), and it is the first organization that is both founded and directed by native Marshall Islanders (Leading Ladies, 2021). ACOM has worked well with both the Marshallese community and the Arkansas state government. They have successfully lobbied the state to include Marshallese children in the state's insurance coverage program for children in low-income homes, provide the driver's test in Marshallese, and have organized health oriented educational events (https://www.arkansasmarshallese.org/). ACOM's strong ties with the local Marshallese community paired with their experience organizing educational events and working with the state government make them an optimal group to collaborate with on Marshallese health issues.

Now that the Marshallese are eligible for Medicaid, it is important to make sure that they are aware of this change and its importance. Previous public health outreach programs have found that cultural sensitivity and community partnership "foster broader community interest and acceptance of the program" (Meade et al., 2007, p. 75). The Arkansas Department of Health came to a similar conclusion during the 2016-2017 mumps outbreak in NWA. The response team found that working with local pastors and Marshallese community groups was necessary to curb the outbreak (Pike et al., 2020, p. 1484). However, it is equally important to work with the Marshallese community on proactive measures like Medicaid enrollment. The ANT analysis shows that in order for the Arkansas health care system to address the needs of the Marshallese, they need to be working with the Marshallese to develop solutions that are tailored to the community.

COLLABORATING WITH MARSHALLESE COMMUNITY GROUPS TO INCREASE MEDICAID ENROLLMENT

In order to help mitigate the determinantal effects of outbreaks like Tuberculosis or Covid-19 in the Marshallese community, healthcare needs to be made more accessible. This will help treat underlying non-communicable disease within the community and make it easier to identify and treat outbreaks before they get out of hand. Increasing Medicaid enrollment will increase healthcare utilization by making it more affordable for the Marshallese to seek care.

Now that Medicaid is available for the Marshallese it is important to maximize the number of Marshallese enrolled. Enrollment events should be held to help community members apply and inform them on the benefits of Medicaid. When dealing with the health care system, the Marshallese often prioritize work and make appointments as early as 4:15 or 4:30 in the morning so that they can be on time for their first shift (McElfish et al., 2020, p. 9). To make the enrollment events as accessible as possible, they should be held on weekends with the possibility of virtual or asynchronous attendance.

For the Marshallese, churches can represent more than religious beliefs. They are often centered around atoll or clan structures. Attendance at churches is very high with families attending together once if not several times a week (Mcelfish et al., 2018, p. 267). The Marshallese are predominantly Christian and the most attend services on Sunday. Holding sign up events after Church services would accommodate work schedules and allow for the involvement of pastors who are well respected in the community. Arkansas currently allows religious gatherings to take place provided that all attendees wear a mask and families are socially distanced so these events would be in compliance with Covid-19 regulations.

The Marshallese are high users of Facebook and the ACOM Facebook page has over

5,500 followers. This makes Facebook a good avenue to advertise future events. ACOM has already posted information regarding the recent changes to Medicaid, so their audience may already be aware of these changes and receptive to a sign-up event. Having ACOM spearhead this effort would help maximize outreach since they already have an established network and credibility within the community. Currently translated applications for Medicaid are only available in paper form, but are expected to be released online later this spring (Kellams, 2021). Early sign-up events would need to have paper applications on hand, but later ones could also provide computers for online registration. In order to maximize enrollment, it would be helpful to work with the Arkansas Department of Health to get funding for paper applications, better access to computers, and provide educational material in both English and Marshallese on the basics of Medicaid.

Providing the Marshallese with Medicaid will likely substantially help their healthcare status. A review of empirical studies was conducted, and it was consistently found that health insurance correlated with an increase in health care utilization and improvement of overall wellbeing (Freeman et al., 2008, p. 1031). When the Marshallese were surveyed, they cited not having insurance and not knowing the benefits of insurance as a barrier to health care. While Medicaid takes care of not having insurance, the Marshallese may still be unsure of how to navigate the healthcare billing system. As mentioned previously, input from both physicians and the Marshallese will be beneficial for creating these handouts. Physicians can provide a level of expertise and insights into common gaps in understanding that they see their patients struggle with. The Marshallese can contribute their own experiences while making sure that information presented is accessible.

From an ANT perspective, it is in the Marshallese's interest to sign up for Medicaid.

Including Marshallese community groups, whose goals align with those of the local community, will help these events be more effective since they will be designed with the communities needs in mind. The Arkansas Department of Health has a vested interest signing up the Marshallese for Medicaid as the Marshallese are Arkansas residents and providing them with insurance will decrease both the financial and human costs of a health care crisis. From a physician's perspective, increasing the number of Marshallese on Medicaid will allow them to be compensated for treating patients that would have been either unable to pay or turned away before they had insurance. While this may generate new patients for physicians, Medicaid patients generate less revenue, and this could discourage physicians from bringing more Medicaid patients to their practice.

FUTURE IMPLICATIONS OF ACTOR NETWORK THEORY AND MARGINALIZED GROUPS IN HEALTHCARE

The Marshallese's health status has been negatively affected by US nuclear testing in the RMI and because of this the Marshallese are distrustful of the US government and the US health care system. Creating health solutions for the Marshallese community will be most successful when multiple actors including local physicians and the local Marshallese population are included in the discussion and implementation process. This partnership will help rebuild trust between the Marshallese and the US health care system. The expected outcome is to minimize the impact that illness, specifically outbreaks, have on the community by making health care more accessible. The hope is that increasing Medicaid enrollment through community partnerships will help the Marshallese better trust the healthcare system and lead to an increase in its usage that will lift the baseline health for the Marshallese population.

In the future, it will continue to be important to look at public health issues through the

lens of ANT so that crucial actors can be identified, and their input can be taken. This will require more effort on the front end of the problem-solving process but the benefits of a culturally appropriate and community driven solution will pay for itself. Future efforts to work with the Marshallese would benefit from more support and integration with the local and state government to help educate and lift the socioeconomic status of the Marshallese.

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