Attending to the Burden of Disease for Isolated Indigenous Populations of the Amazon:

An Experience with Expedicionários da Saúde

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
in the Graduate School of Duke University

2015
ABSTRACT

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Abstract

**Background:** Indigenous People around the world experience inequalities in health care. In Brazil, Indigenous inequalities in health are exacerbated by the poor system of health care delivery. The aim of this study is to understand barriers to care as defined from the Indigenous perspective.

**Methods:** This study was conducted on three Indigenous reserves of the Xavante people in Mato Grosso, Brazil. We utilized a mixed methods approach. In the quantitative portion of the study, we surveyed 50 individuals using an adapted version of the World Health Organization 2002 World Health Survey. Participants for the quantitative survey were recruited from a randomized list of prospective patients for a medical outreach mission. In the qualitative portion of the study, we interviewed 37 individuals, including patients, health care providers, and village chiefs, about their experiences with health care. Participants for the qualitative interviews were recruited randomly from a medical outreach patient listing (Expedicionários da Saúde).

**Results:** Overall, participants reported dissatisfaction with health-seeking experiences. We identified five barriers to obtaining satisfactory care: lack of transportation, lack of health care services and medication, attitudes of health care workers, lack of culturally appropriate services, and social determinants.

**Conclusions:** Given an overall sense of dissatisfaction with health care use among indigenous people, future research should focus on identifying interventions to help overcome key barriers to accessing care. Private-public partnerships and other innovative health systems models should be explored to meet the needs of underserved indigenous communities.
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1. Introduction

Indigenous People have the worst health outcomes and poorest socioeconomic status of all minorities populations in the world (Gracey & King, 2009). Indigenous communities struggle with a high burden of infectious disease, high infant and maternal mortality, high prevalence of malnutrition and lower life expectancy (Gracey & King, 2009). They are also confronted with on-going threats from discriminatory government policies that contribute to the degradation of indigenous economies, destabilization of socio-political structures, and destruction of traditional lands (Economic, 2009). While numerous international and regional organizations attempt to help through providing aid or advocacy, the challenge of resolving inequalities in Indigenous health, however, is unique. Indigenous health is intimately linked to the social and political environments in which they live. Addressing health issues therefore requires multifaceted approaches to confront social problems through engagement of Indigenous notions of health and empowering Indigenous autonomy. (Nettleton, Napolitano, & Stephens, 2007).

Research has revealed a number of barriers Indigenous people face in accessing and utilizing health care. The geographic isolation of many indigenous communities incurs significant costs related to accessing care which include out-of-pocket fees for transportation, food and accommodation in urban centers where most hospitals are located, family care responsibilities, the high costs of medication and health care services, and the economic losses due to missed workdays (PAHO, 2006). Misguided perceptions of Indigenous beliefs and practices often results in the provision of culturally inappropriate care which neglects Indigenous systems of health (Economic, 2009). In addition to these challenges, a weak system of government-administered
primary care fails to support populations already suffering from high rates of disease and poverty, thus perpetuating inequalities in health (Economic, 2009).

While the Indigenous peoples of Brazil comprise only a fraction of the total population, they bear a disproportionately high burden of the country’s morbidity and premature mortality. Despite drastic improvements in maternal and child health, Indigenous populations still face abnormally high rates of infant mortality. A 2003 study demonstrated that the infant mortality rate within a Xavante community (indigenous Brazilian population) was 103 per 1000, which three-fold greater than the national average which was 31 per 1000 (Montenegro & Stephens). Rates of chronic malnutrition and stunting in Indigenous communities are high – 5.9% and 25.7% compared to 4.0% and 7.4% respectively (Horta et al., 2013). With the prevalence of non-communicable diseases on the rise in Brazil, Indigenous populations are now especially vulnerable. Increasing contacts with packaged foods and deforestation have imposed changes to natural indigenous dietary practices. Obesity rates are as high as 50% in some communities (C. E. Coimbra Jr, Flowers, Salzano, & Santos, 2004), and diabetes, a disease previously unknown to many indigenous communities, is becoming a significant problem, with one indigenous community having a diabetes prevalence of 28.2% compared to the national average of 8% (Dal Fabbro et al., 2013). Mental health issues disproportionately affect indigenous populations; the suicide rate in some indigenous communities is approximately seven times higher than the national average (de Souza & Orellana, 2012). In the last decade, the Brazilian Ministry of Health has invested in developing a system of primary care specifically for Indigenous communities to help combat high rates of disease; however, access to quality care for the numerous isolated

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1 For additional information, see http://saladeimprensa.ibge.gov.br/en/noticias?view=noticia&id=1&busca=1&idnoticia=278.
Indigenous communities of the Amazon remains limited (Pantoja, Orellana, Leite, & Basta, 2014).

To better understand the drivers of poor indigenous health in Brazil, we must first evaluate the current health care system. Health care became a universal right in Brazil as of the 1988 constitution. Indigenous populations were not entitled to this privilege until 1996 when the Brazilian government formed the National Indigenous Health Policy (Paim, Travassos, Almeida, Bahia, & Macinko, 2011). To cater to the specific needs of Indigenous communities, the Ministry of Health created a system of decentralized health care – known as the Indigenous sub-health care system (SESAI). Today Indigenous people can receive basic health services from health professionals on their traditional lands. Indigenous communities are also encouraged to participate in the planning and organization of their own health care system. The availability of basic health services at the village level has contributed to some improvement in Indigenous health. With a formal health system in place, the government implemented numerous vaccine programs that significantly reduced the number of deaths due to infectious diseases – some of which nearly wiped out Indigenous communities only 20 years earlier. However, implementation of the indigenous health care system has been largely inefficient (Athias & Machado, 2001). The availability of resources is often limited due to bureaucratic delays, dysfunctional health information systems, mismanagement of health care workers, and overall poor quality of care (Cardoso, 2014). Unmet health care needs among indigenous communities has lead to political strife and protests by Indigenous leaders demanding better services (Novo, 2011).
As demonstrated with the Indigenous in Brazil, poor health system performance exists when there is a gap between patient expectations of and experiences with health care. Patient satisfaction is considered a standard measure of this gap in health service provision and has been used in global evaluations to drive health system improvement (Schäfer et al., 2015). Understanding determinants of patient satisfaction with care also helps us understand care-seeking behaviors and subsequent utilization of care, two factors key to health system performance (Ware Jr & Davis, 1983).

The contextual environment therefore has become a key research focus to understand the role of behavioral determinants in the utilization of health care. A recent review illustrates the dependence of utilization on, “demographic factors, social structures, level of education, cultural beliefs and practices, gender discrimination, status of women, economic and political systems environmental conditions, and the disease pattern and health care system itself” (Shaikh & Hatcher, 2005). Traditional beliefs fused with actual experience shape individual perceptions of symptoms and are believed to manifest in specific patterns of health seeking behaviors, such as home-treatment, delay in seeking biomedical treatment and non-compliance with referral advice itself. Additionally, perceived attitudes of health providers and patient satisfaction with the treatment, factor into decisions regarding health seeking and utilization (Ndyomugyenyi, Neema, & Magnussen, 1998). A recent study of primary care utilization by pregnant women in rural Vietnam demonstrated that client-perceived quality of the services provided, as well as socio-cultural and economic factors, were more important determinants to the utilization of delivery services (Duong, Binns, & Lee, 2004). However, research into factors affecting utilization of care specifically in indigenous populations of Brazil has been limited.
While the current Brazilian government wants to address inequalities in indigenous health, a lack of research contributes to ill-informed health care policies, which fail to address the needs of the indigenous people. Previous research has examined health care utilization in order to understand factors that limit access to care in low-income communities (Miquilin Ide, Marin-Leon, Monteiro, & Correa Filho, 2013). Further, similar studies have been used to help improve government health care programs (Fernandes, Bertoldi, & Barros, 2009). With a significant lack of information on indigenous populations, our ability to produce successful interventions is limited (Santos et al., 2011). Given the increasing burden of disease and unique social factors indigenous Brazilians face, more research on the behavioral determinants of health in indigenous populations is needed.

1.1 Research Question

Given the need for research on attitudes and experiences of health care service use, the central research question of this thesis is “What are the challenges unique to Isolated Indigenous people that most significantly affect utilization of health care?” Within this area of study, I have outlined two specific research aims:

- **Specific Aim 1:** To understand the socio-behavioral determinants of seeking health care.

- **Specific Aim 2:** To understand perceived barriers to receiving health-care as an Indigenous person.

Below, I first present a systematic review of the literature on indigenous health care services in Brazil. This review sets the stage for the current status of knowledge and the gaps in our understandings of health care attitudes and use. Following the
systematic review, I described the mixed methods approach to study indigenous health care determinants of care-seeking and perceived barriers to care.

1.2 Systematic Review of Research on Indigenous Health Services in Brazil

1.2.1 Introduction

Indigenous people worldwide continue to face poor standards of health and low socioeconomic activity (Gracey & King, 2009). Of the approximately 400 million inhabiting each continent, 896,917 live in Brazil (IBGE 2010 Census). While they only make up 0.5% of the total Brazilian population, they occupy 12% of its total land mass. The impact of colonization, that brought slavery, disease, and genocide, reduced a total population of five million to 120,000 in 1950 (Maggi, 2014). Indigenous health care was not considered by Brazil until 1910 with the creation of the Indian Protection Service; however, some communities contacted by catholic missionaries received a mix of health care before. Even then, widespread government corruption created land conflicts perpetuating violence against the indigenous and numerous outbreaks of infectious disease. The creation of the National Indian Foundation (FUNAI) in 1967, and the recognition of the rights of indigenous Brazilians in the 1988 national charter represented prioritization of the health of the Indigenous. In the years that followed a network of sanitary districts (DSEI) was set up as the “operational basis for SUS health care policy for indigenous populations.” (Maggi, 2014). However, challenged by inexperience and poor organizational capacity responsibility for indigenous health care was passed from FUNAI to the Ministry of Health and then to a specific department called the Special Indigenous Health Department, set-up by the ministry of health.” (Maggi, 2014). Meanwhile many indigenous populations were suffering from higher
mortality rates due to respiratory and infectious diseases (Ferreira, Matsuo, & Souza, 2011), or in other regions, significantly higher rates of suicide (Erthal, 2001). The final organizational restructuring of indigenous care occurred recently, where in 2011 SESAI partnered with a number of social organizations, specifically, the Instituto de Medicina Integral Prof. Fernando Figueira (IMIP) to improve the organization and implementation of “Basic Indigenous Health Care.” (Maggi, 2014).

To date, however, there have been no systematic reviews conducted on the health care services and interventions provided to the Indigenous populations of Brazil. Researchers in the past have conducted literature reviews to report on the worsening health outcomes and socioeconomic conditions amongst Indigenous populations worldwide. In 2006 the Lancet published a series of reviews on Indigenous Health from a continental perspective. Specifically in Latin America they highlight the high rates of maternal and child mortality and higher rates disease morbidity, in context of widespread poverty, unemployment, poor education, poor access to clean water and nutrition (Montenegro & Stephens, 2006). While their analysis covers the significant health and socioeconomic factors underlying this disparity, they do not pay as much attention to the type of health care services, or interventions being provided. Other studies have looked at the effectiveness of specific types of interventions, generally using either rates of mortality or hospital admission as a metric. One example includes a study conducted by Gruen et al. 2006, which assessed the impact of a specialist outreach service to disadvantaged communities, including a region with a large number of indigenous communities (Gruen, Bailie, Wang, Heard, & O’Rourke, 2006). However, this intervention does not reflect the services available to the indigenous in Brazil.
Prior literature reviews on Indigenous Health in Brazil have provided to an accumulating evidence base demonstrating the significant health and socioeconomic disparities to non-indigenous counterparts. Further, policy makers have used data on health and socioeconomic indicators, summarized by these reviews, to form specific objectives for improving the Indigenous situation. The expected outcome of this review was a comprehensive profile of the types of health care services and interventions being provided to the indigenous people of Brazil; and rather to generate an evidence base upon which the global community can evaluate these services to improve indigenous health.

1.2.2 Methods

This systematic review on indigenous health care was initially conducted on October 25th, 2014. Articles were identified on Pubmed NCBI (http://www.ncbi.nlm.nih.gov/pubmed/) using the following search terms: “Indigenous” AND “healthcare” and “Brazil”. This search was replicated using another database (Web of Science), from which no new articles were found. An initial abstract review was first conducted to rule out articles lacking data. Figure 1. depicts the complete search strategy.

1.2.3 Inclusion & Exclusion Criteria

Table 1 lists the inclusion and exclusion criteria used to identify candidate articles for further review and eliminate irrelevant information to the analysis. The goal of this review is to identify sources of health care provided to the indigenous Amazonian populations of Brazil. Therefore articles which focused on non-indigenous populations or indigenous populations outside of Brazil were excluded from the study.
Furthermore, epidemiological or anthropological studies were specifically excluded as they either do not describe actual health care services/interventions or provide pertinent and reliable information. Furthermore, secondary studies or opinion articles that were considered to lack original data or information on health care services were excluded for the same reasons as just mentioned (for epidemiological and anthropological studies). Finally, Figure 1 depicts the search strategy and results of the inclusion/exclusion process.

1.2.4 Article Limitations

The following headers describe the specific information, which was obtained from each of the candidate articles: authors, title, intervention or existing care, type of care, purpose of study, findings, specifically describes inequality, comments. Additionally, limitations of each article were acknowledged by the author during the final in-depth review of the articles.
Systematic Review of **Indigenous health care in Brazil**

![Diagram](image)

**Figure 1.** Search strategy and results of article review

**Table 1.** Inclusion and exclusion criteria for initial abstract review

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Describes current health care interventions or existing care</td>
<td>1. Epidemiological/prevalence studies or anthropological studies not directly related to health care</td>
</tr>
<tr>
<td>2. Focuses on specifically an indigenous population</td>
<td>2. Does not have original data on intervention or existing care</td>
</tr>
<tr>
<td>3. Contains original data</td>
<td>3. Not specific to Brazil</td>
</tr>
<tr>
<td>4. Focuses on Brazil</td>
<td></td>
</tr>
<tr>
<td>7 articles excluded</td>
<td>1 Commentary</td>
</tr>
<tr>
<td>3 Study missing</td>
<td>10 Anthropological study without data on intervention</td>
</tr>
<tr>
<td>4 No data</td>
<td>7 No primary data on direct interventions</td>
</tr>
<tr>
<td>52 articles excluded</td>
<td>1 Repeated study (Rissardo et al, 2014)</td>
</tr>
<tr>
<td>1 Commentary</td>
<td>12 Epidemiological study</td>
</tr>
<tr>
<td>10 Anthropological study without data on intervention</td>
<td>5 Not specific to Brazil</td>
</tr>
<tr>
<td>7 No primary data on direct interventions</td>
<td>15 Irrelevant to indigenous health care</td>
</tr>
</tbody>
</table>

**1.2.5 Results**

The literature on indigenous health care services and interventions is sparse. Of the 24 studies included a majority, 14 of 24 articles, described existing health care, while
the remaining ten described interventions. As shown in table 2, nine of the twenty-four studies focused on care related to infectious disease (two on HIV and syphilis, five on tuberculosis, one on anaemia and malaria, and one on measles). Over fifty percent (five out of the nine studies) of these studies focused on tuberculosis care. Primary health care was the next most studied topic, 6 of 24 studies.

Brazil is broken down into 4 geographic regions: the Northern Amazon region, the Northeast, the Center-West region, and the Southern region. A majority (14/24) of the studies were conducted in the Southern region, whereas only five studies were conducted with indigenous communities located in the Northern Amazon and Northeastern regions. Of the approximately 250 ethnic groups believed to inhabit Brazil (King, Smith, & Gracey, 2009), only twelve were addressed in these studies only discussed. However, seven of the studies analyzed the overall, which is assumed to include all of the Brazilian indigenous groups. Ten of the twenty-four studies were conducted with the Guarani and Kaingang, two indigenous groups that inhabit the Southern states of Brazil. Only two of the studies focused on the Yanomami, who are experiencing declining health outcomes due to poor quality care (or more information see this website: http://www.survivalinternational.org/news/9711).

In regards to issues faced, the 6 articles on primary health care and the 3 on the organization of care mentioned poor capacity, lack and mismanagement of resources. As elaborated on in the authors of the three articles about indigenous health suggested that poor training, teamwork, and ambiguities of responsibilities contributed to their limited efficacy. Finally, cultural sensitivity was cited as a common issue (referenced in 14/24 articles). These authors mentioned cultural sensitivity and indigenous participation as key factors in designing future interventions.
1.2.6 Discussion

The goal of this systematic review was to identify the current state of knowledge around indigenous health care in Brazil. The proposed search strategy and review process twenty-four articles evaluating existing health services or interventions to improve indigenous health. The most significant finding was the high representation in the literature of indigenous communities in the Southern geographic region of Brazil. Specifically, ten of the twenty-four studies were conducted with the Guarani and Kaingang peoples. As mentioned in the results, these two ethnicities represent less than 0.0008% of the different indigenous ethnicities in Brazil (King et al., 2009). In fact the majority of indigenous peoples live in the North and Northeastern regions, representing 63% of the total indigenous population (IBGE, 2010). Coimbra & Santos have attributed this significant misrepresentation to the lack of information systems to track the indigenous people in these regions (C. E. A. Coimbra Jr & Santos, 2000). In a later study he conducted on the blood pressure of the Xavante, he calls attention to the lack of research on indigenous health in Brazil (C. Coimbra Jr, Chor, Santos, & Salzano, 2001).

Another significant finding was the high proportion of studies that cited poor indigenous engagement and cultural awareness as sources of failure. This finding is unsurprising given that discrimination is still a significant issue amongst the indigenous in Brazil (Maggi, 2014). Barriers resulting from this discrimination have implications in health care (Marrone, 2007). Communication has been cited to cause problems when implementing health care interventions (Ghiggi Junior & Langdon, 2014) Cardoso et al. extends the issue of communication past basic language differences. Reflecting on
previous indigenous health policies, he mentions that issues of social control and cultural inconsistencies compromised the indigenous health system (Cardoso, 2014). The challenges experienced with the Indigenous Health worker program highlighted in this review, provide examples of such. Specifically, elections of indigenous health workers by healthcare staff caused problems as they were inconsistent with native social patterns (E. E. Diehl, Langdon, & Dias-Scopel, 2012).

Finally, poor access and health inequality remains a significant issue. In Brazil indigenous rights is recognized in the 1988 constitution. The resulting change to universal health care did create a national priority to improve indigenous health. However, as mentioned by Alex Shankland, “Despite these achievements, inequities in access remain an important barrier to universal coverage, in particular for marginalized groups such as indigenous peoples.” (Coelho & Shankland, 2011). In a recent UN report on, “State of the World’s Indigenous Peoples” the infant mortality rate in Amazonas state is 43.9 per 1,000 births, compared to the national average of 19 per 1,000 births. In 2004, the malaria incidence among indigenous peoples was 70 times higher than the national average (Economic, 2009). In a recent national survey of indigenous health which showed a significant trend of malnutrition and obesity amongst indigenous children and women (30.8% of the measured population), the authors suggest that the, “observed disparities in health indicators underscore that basic healthcare and sanitation services are not yet as widely available in Brazil’s indigenous communities.” Future research should investigate innovative strategies to improve access to health care.
1.2.7 Implications and Recommendations

This reviewed aimed to produce a comprehensive account of the health care services provided to the indigenous populations of Brazil. Decentralization and resulting government initiatives have failed to improve the health care for indigenous people, as evidenced by the growing inequality. Future initiatives should instead be driven by evidence. Given the lack of research and rather organization, future systematic reviews of this style could help create generate such an evidence base and coherent structure guiding innovative policy change.

1.2.8 Limitations

The study included limitations of language and of a single reviewer. A number of the papers included in this review were originally published in Portuguese, and were therefore translated into English by Google translator. However, the author is proficient in the language and was able to check for inconsistencies between versions. Secondly, since only a single reviewer chose the articles, there could have been selection bias that affected the choice of articles included.
2. Methods

2.1 Overview:

As stated above, the primary question for this study was “What are the challenges unique to Isolated Indigenous people that most significantly affect utilization of health care?” Mixed methods were employed to address two aspects of this: (Specific Aim 1) To understand the socio-behavioral determinants of seeking health care; and (Specific Aim 2) To understand perceived barriers to receiving health-care as an Indigenous person.

2.2 Setting

The Xavante people are one of many ethnic Indigenous groups resident to Brazil. Historically, the Xavante people have occupied the central plateau region of Brazil, now contained mostly by the state of Mato Grosso. The Xavante were once a semi-nomadic tribe. It is believed periods of intense migration through the eastern and central regions of the Mato Grosso plains were characteristic of these people (Lopes da Silva & Cunha, 1992). In the decades proceeding the pre-contact era (before the 1940s) the Xavante territory came under intense demarcation by government headed initiatives to establish the nation’s capital of Brasilia (Santos, Coimbra Jr, & Welch, 2013). Efforts to economically transform this “wilderness” region via road and infrastructure development resulted in the expulsion of the Xavante from their land. Further development forced populations into a confined yet fragmented network of 10 small patches of land (Santos et al., 2013). Subsequent periods of intense conflict and persecution by the government and industrial developers forced the Xavante people to further migrate within smaller regions of land. Co-burdened with high rates of mortality
due to emerging infectious disease epidemics, thought to arise from contact with society, and drastically impacted the population size (Coimbra Jr, Flowers, Salzano, & Santos, 2004b).

A period of failed government assistance programs followed. Such initiatives were aimed towards integrating Xavante into the economy, built on seized land, including a program to promote rice production within the Xavante communities (Coimbra, 2002). Despite the failure of these programs, further dependence on government assistance and departure from traditional practices (i.e. agriculture) ensued (Santos, 2013). In fact, recent studies have in fact suggested a detrimental effect of these programs on Xavante health, for example resulting dietary changes following the implementation of the rice program has contributed to the demographic and health transitions of the Xavante characteristic by higher levels of obesity marked by higher average BMI (Santos, 2013) (Welch et al., 2009).

Today the Xavante territory occupies the eastern regions of Mato Grosso, where approximately 14,500 individuals occupy nine separate indigenous reserves (Figure 1.). Before further discussion, it is important to consider the substantial limitations in studying the demographics of the Xavante, as well as many other Indigenous populations, due to the lack of information available. The few studies conducted on the Xavante people have utilized household survey data collected by the Health Services Information System (SIASI) of FUNASA. A recent demographic assessment of the population spread across the different reserves displays a population dominated by young individuals (40% of the population is less than 5 years of age). The burden of infectious and parasitic diseases remains the leading causes of death (Coimbra et al.,
2013). However, recent studies of the nutritional status of various Xavante populations indicate the emergence of high levels of obesity and previously uncharacterized non-communicable diseases, such as diabetes and hypertension (Coimbra Jr et al., 2004b). Some attribute such nutritional transition to the adoption of a westernized diet and reduction in physical activity (Coimbra Jr, Flowers, Salzano, & Santos, 2004a). Overall, current and future health profile of the Xavante requires attention for both curative and preventative centered care.

Currently, the health system for the Indigenous is implemented and regulated by a division of the ministry of health called FUNASA (National Health Foundation). The Indigenous people were to receive “culturally appropriate” care through the Special Indigenous Health Districts (DSEI). Within each village there is a DSEI health post staffed by local indigenous workers, who provide basic primary care services, such as providing routine prenatal care, administering first aid, and treating common diseases (Coimbra Jr et al., 2004b). The primary health system in place for the Xavante is composed of four basic sub-units, based out of Barra do Garças. Each basic health unit and corresponding medical team works with local Xavante health workers in their respective villages (Coimbra Jr et al., 2004b). Improvements in access to care have been observed in the context of this new system, where rates of hospitalization have significantly increased. These findings, however, are underscored by the fact that more than 50% of hospitalizations were caused by respiratory, nutritional, infectious and parasitic diseases, otherwise preventable causes at the level of primary health care, thereby questioning the efficacy of the system (Lunardi, Santos, & Coimbra Jr, 2007).
In designing a culturally appropriate health care system, an attempt to integrate local participation in the provision of care was necessary. FUNASA has stressed the importance of community involvement in the implementation and management of DSEI through local leadership (Coimbra Jr et al., 2004b). Yet a striking contrast exists when it comes to the utilization of care through this system. Since many Xavante have had to travel to tertiary centers for care, they are aware of the discrepancies in the quality of care they receive, and therefore are unwilling to accept these inferior services (Coimbra Jr et al., 2004b).

2.3 Participants

Participants were recruited by the author and the local translator using a list of triaged individuals for the planned Expedicionários da Saúde medical expedition. Individuals from the triage list were located at convenience on random walks through the villages where data collection took place. Only consenting participants above the age of 19 were eligible to participate in the study. Permission to conduct research was obtained from the chief of each village prior to data collection. Individual qualitative interviews were then conducted with the chief, if he was interested.

2.4 Procedures

The survey was translated into Portuguese by the study author, and culturally adapted by a local Xavante representative. The survey was piloted during the cultural adaptation phase with representatives of the Xavante people (Warã Association). The survey was administered in Portuguese by a trained local translator and in the local language when the respondent did not feel comfortable answering in Portuguese. The translator and the study author sampled respondents randomly, in each of the villages.
visited. This study was approved by the Duke University Institutional Review Board, Office of Research Support (protocol number C0303) and by the local Xavante representatives of the Warã association. The author also received permission from the indigenous leaders in each of the villages visited. Informed consent was obtained orally prior to the survey after translator informed each participant of the purpose of the study.

2.5 Measures

I plan to explore the barriers to health care and the socio-behavioral determinants associated with Indigenous utilization of government-administered care. Over the course of a medical outreach expedition with Expedicionários da Saúde, a mixed methods approach was used to understand Indigenous attitudes and perceptions of the government-administered Indigenous health care system.

2.5.1 Quantitative Measures

The goal of the quantitative section was to obtain self-reported health-seeking behavior and corresponding challenges faced while seeking care. The survey template was derived from the World Health Survey, previously administered in Brazil by the World Health Organization in 2003. Specifically, the section on “Health System Responsiveness” was considered for questions asking about specific challenges faced while seeking care.
2.5.2 Qualitative Measures

A series of individual interviews were conducted with a random selection of respondents to the quantitative survey. These individuals were asked to elaborate on their response to the following question:

“In general would you say that you are satisfied or unsatisfied with indigenous health care in your community? What about in your country?”

Additionally, non-structured conversations with chiefs from 4 of the villages that were visited, as well as 5 local residents and 2 medical staff, about local health care were recorded. Each response was recorded by the author, using an electronic tape recorder, and later transcribed and translated into English by the author and a native Brazilian Portuguese speaker.

2.6 Analysis

Survey responses were collected and entered into an excel spreadsheet by the author at the time of they were given. Data were then cleaned and summarized in a separate excel document. Descriptive statistics were conducted on the data using Stata 13.0. Further statistical tests were not conducted due to the small sample size (n=50).

Interview responses were recorded using a digital voice recorder (Sony IC recorder ICD-PX333). Responses that were given in Xavante were translated into Portuguese by the local translator and also recorded using the digital voice recorder. Audio files were transcribed and translated by the author, and reviewed by a research assistant with native level Portuguese language skills. Transcripts were subsequently
uploaded and analyzed in NVIVO12 for Mac. Qualitative analysis of the interview transcripts followed the Framework Approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Thematic nodes were formed after an initial review of 3 transcripts. The remaining transcripts were then reviewed and analyzed for content applying to the pre-determined nodes. Electronic data and audio files were stored on an encrypted laptop. Back-up copies of the files were also stored on an encrypted external hard drive.

3. Results

3.1 Quantitative

3.1.1 Demographics

We were able to sample individuals from four of the seven official Xavante territories: 1 from Culune, 15 from Parabubure, 26 from Sangradouro, and 8 from São Marcos, giving a total of 50 individuals responded to the quantitative survey. Of the 50 individuals, 38 (76%) were male while 12 (24%) were female. The mean age of respondents was 51.38 years, with a standard deviation of 21.17 and range of 19-94. More than half of the respondents were unemployed (n=29, 58%); while the most common types of employment among the minority of those employed were: Professor (n=8), FUNAI service worker (n=4), or Indigenous health worker (n=3). The mean number of individuals per respondent's household was 7.76 (SD = 3.84 and min/max = 3/19). Most of the respondents had no formal education (n=30, 60%), while the remainder had either completed primary school (n=8, 16%), secondary school (n=10, 20%), or high school (n=2, 4%).
Table 2. Demographic characteristics of respondents to the quantitative survey

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total sample</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>50</td>
<td>1.00</td>
</tr>
<tr>
<td>Male</td>
<td>38</td>
<td>0.76</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td>0.24</td>
</tr>
<tr>
<td><strong>Age (Years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>51.38</td>
<td></td>
</tr>
<tr>
<td>STD</td>
<td>21.17</td>
<td></td>
</tr>
<tr>
<td>min/max</td>
<td>19/94</td>
<td></td>
</tr>
<tr>
<td><strong>Household size</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>49</td>
<td>1 missing</td>
</tr>
<tr>
<td>mean</td>
<td>7.76</td>
<td></td>
</tr>
<tr>
<td>STD</td>
<td>3.84</td>
<td></td>
</tr>
<tr>
<td>min/max</td>
<td>3/19</td>
<td></td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>50</td>
<td>1.00</td>
</tr>
<tr>
<td>Employed</td>
<td>21</td>
<td>0.42</td>
</tr>
<tr>
<td>Unemployed</td>
<td>29</td>
<td>0.58</td>
</tr>
<tr>
<td><strong>Highest level of education completed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>50</td>
<td>1.00</td>
</tr>
<tr>
<td>No formal education</td>
<td>30</td>
<td>0.6</td>
</tr>
<tr>
<td>Primary school</td>
<td>8</td>
<td>0.16</td>
</tr>
<tr>
<td>Secondary school</td>
<td>10</td>
<td>0.2</td>
</tr>
<tr>
<td>High School (or equivalent)</td>
<td>2</td>
<td>0.04</td>
</tr>
</tbody>
</table>
3.1.2 Descriptive statistics on Questionnaire responses

Most of the respondents answered yes to, ‘In general I would say that I am a healthy person’ (n=32, 64%), but also to, ‘Do you have any health problems that prevent you from doing any of the things people of your age can normally do’ (n=28, 56%). Just over half of the respondents had previously received care from a health clinic (n=26, 52%), with the majority of these visits occurring in the last year (n=18, 36%). Reasons for visit included: Injury, acute concerns, musculoskeletal, surgical related, obstetric, chronic disease, and physical exams (table 1.).

Of the 24 individuals (two responses were missing) who had previously received care, 9 felt that they received the care that would help treat their condition, based on the following reasons, that were provided in the questionnaire: could not afford the cost of visit (n=2/9), felt the provider’s drugs or equipment was inadequate (n=6/9), felt the provider’s skills were inadequate (n=5/9), was told to see another provider (n=2/9). The majority of respondents expressed dissatisfaction with the primary care system in their community (n=30, 60%), and with Indigenous health care in all of Brazil (n=33, 68%).

Respondents were then asked the following two questions: “Have you ever been unable to receive health care when you needed it?” and “Have you ever avoided the health post when you felt sick?” We found that 14/50 individuals were unable to receive care when need, and 16/50 reported having avoided seeking health care from the health post when needed. For the 13 of the individuals who reported being unable to receive health care when previously needed, the following reasons, provided by the questionnaire, best explained why: didn’t know where to go (n=6/13), did not have transport (n=8/13), could not afford to pay for transport (n=7/13), tried but were denied
care (n=6/13), could not take time off work or commitments (n=9/13). For the 16 individuals who reported having avoided seeking health care from the health post when previously needed, the following reasons, provided by the questionnaire, best explained why: treated poorly in the past (n=9/16), respondent thought that they were not sick enough (n=3/16), respondent did not believe the provider would help (n=11/16). Yet, when asked whether they would go somewhere else to receive care the majority of these 16 individuals responded “no” (n=11/16). Similarly, a majority of these individuals did not receive care after avoiding the health post (n=13/16).
<table>
<thead>
<tr>
<th>Primary Questions</th>
<th>Follow-up Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>When was the last time you sought care from the local health clinic?</strong></td>
<td><strong>Reason for visit:</strong> n = 24 (2 missing) (%)</td>
</tr>
<tr>
<td>Responses n = 50 (0 missing) (%)</td>
<td>Injury 3 0.12</td>
</tr>
<tr>
<td>In the last year 18 0.36</td>
<td>Acute concerns 3 0.12</td>
</tr>
<tr>
<td>1-2 years 2 0.08</td>
<td>Musculoskeletal 5 0.19</td>
</tr>
<tr>
<td>2-3 years 1 0.02</td>
<td>Surgical related 3 0.12</td>
</tr>
<tr>
<td>3-5 years 1 0.02</td>
<td>Obstetric 2 0.08</td>
</tr>
<tr>
<td>&gt; 5 years 2 0.04</td>
<td>Chronic Disease 4 0.15</td>
</tr>
<tr>
<td>Total 26 0.52</td>
<td>Physical exam 4 0.15</td>
</tr>
<tr>
<td>Never 24 0.48</td>
<td></td>
</tr>
<tr>
<td><strong>Did you receive the help that you felt would treat your condition?</strong></td>
<td><strong>Reasons why respondent answered “no”:</strong> n = 9 (0 missing) (%)</td>
</tr>
<tr>
<td>Responses n = 24 (2 missing) (%)</td>
<td>Could not afford the cost of the visit 2 0.22</td>
</tr>
<tr>
<td>Yes 15 0.625</td>
<td>Felt the provider’s drugs or equipment was inadequate 6 0.66</td>
</tr>
<tr>
<td>No 9 0.375</td>
<td>Felt the provider’s skills were inadequate 5 0.55</td>
</tr>
<tr>
<td></td>
<td>You were told to see another provider 2 0.22</td>
</tr>
<tr>
<td><strong>In general would you say you are satisfied or unsatisfied with the way the health care system is run...</strong></td>
<td></td>
</tr>
<tr>
<td>Responses n = 50 (0 missing) (%)</td>
<td><strong>...for the Indigenous people in Brazil?</strong> n = 49 (1 missing) (%)</td>
</tr>
<tr>
<td>Satisfied 20 0.4</td>
<td>Satisfied 16 0.33</td>
</tr>
<tr>
<td>Unsatisfied 30 0.6</td>
<td>Unsatisfied 33 0.67</td>
</tr>
<tr>
<td><strong>Have you ever been unable to receive health care when you needed it?</strong></td>
<td><strong>Reasons why respondent answered “yes”:</strong> n = 13 (1 missing) (%)</td>
</tr>
<tr>
<td>Responses n = 50 (0 missing) (%)</td>
<td>Didn’t know where to go 6 0.46</td>
</tr>
<tr>
<td>Yes 14 0.28</td>
<td>Did not have transport 8 0.62</td>
</tr>
<tr>
<td>No 36 0.72</td>
<td>Could not afford to pay for transport 7 0.54</td>
</tr>
<tr>
<td></td>
<td>You tried but were denied care 6 0.46</td>
</tr>
<tr>
<td></td>
<td>Could not take time off work or commitments 9 0.69</td>
</tr>
<tr>
<td><strong>Have you ever avoided the health clinic when you felt sick (or in need of care)</strong></td>
<td><strong>Reasons why respondent answered “yes”:</strong> n = 16 (0 missing) (%)</td>
</tr>
<tr>
<td>Responses n = 50 (0 missing) (%)</td>
<td>You were treated poorly previously 9 0.56</td>
</tr>
<tr>
<td>Yes 16 0.32</td>
<td>You thought that you were not sick enough 3 0.19</td>
</tr>
<tr>
<td>No 34 0.68</td>
<td>You did not think the provider would help 11 0.69</td>
</tr>
<tr>
<td><strong>Did you receive care from another place?</strong> n = 16 (0 missing) (%)</td>
<td></td>
</tr>
<tr>
<td>Yes 3 0.19</td>
<td></td>
</tr>
<tr>
<td>No 13 0.81</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Quantitative survey responses summarized.
3.2 Qualitative

3.2.1 Demographics

A total of 35 individuals participated in the qualitative portion of the study. Of the 35 participants, 23 also responded to the questionnaire. We also interviewed 4 community leaders, 2 local health care workers and 6 patients from the Expedicionários da Saúde medical outreach clinic. The mean age of respondents from the questionnaire was 47.2 (STD = 21.3, min/max=20/43). The mean age of the four community leaders was 76, and their resident villages were: Sangradouro, Abelinha, Nossa Senhora da Guadalupe and São Marcos. We were unable to use 9 interviews: 7 of the interviews could not be translated and 2 of the interviews had too much noise interference to be able to transcribe.
Table 4. Demographic characteristics of participants in the qualitative interviews

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Respondents</th>
<th>Age</th>
<th>Indigenous Territory</th>
<th>Villages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire</td>
<td>n 23</td>
<td>mean 47.2</td>
<td>Sangradouro</td>
<td>Sangradouro 12</td>
</tr>
<tr>
<td></td>
<td>males 20</td>
<td>STD 21.3</td>
<td></td>
<td>Abelinha 2</td>
</tr>
<tr>
<td></td>
<td>females 3</td>
<td>min/max 20/43</td>
<td>São Marcos</td>
<td>Nossa Senhora da Guadalupe 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Nossa Senhora da Guia 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>São Marcos 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Corpo de Cristo 1</td>
</tr>
<tr>
<td>Chief’s speech</td>
<td>n 4</td>
<td>mean 76</td>
<td>Sangradouro</td>
<td>Sangradouro 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>STD 9.8</td>
<td></td>
<td>Abelinha 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>min/max 70/87</td>
<td>São Marcos</td>
<td>Nossa Senhora da Guadalupe 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>São Marcos 1</td>
</tr>
<tr>
<td>Local Health Care Workers</td>
<td>n 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dental Surgeon 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Visiting physician 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EDS patients</td>
<td>n 6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sangradouro</td>
<td></td>
<td></td>
<td>Sangradouro 1</td>
</tr>
<tr>
<td></td>
<td>São Marcos</td>
<td></td>
<td></td>
<td>São Marcos 1</td>
</tr>
<tr>
<td></td>
<td>Parabubure</td>
<td></td>
<td></td>
<td>São Pedro 3</td>
</tr>
</tbody>
</table>
3.2.2 Interview Responses

Using the framework approach (Gale et al., 2013) we identified 4 common themes amongst participants’ explanation of problems with the local health care system:

The theme Social Determinants of Health was assigned to quotes where the respondents’ reference social factors as a cause/driver of their poor health and reason for being unsatisfied with the health care system. Here we defined social factors as the components of life outside direct medical care. Some examples we considered include as lack of employment, quality of education, or poverty. The general attitude that changes in medical care wouldn’t resolve the community’s problems was what we were looking for.

The theme Lack of services and medication was assigned to respondents’ direct complaints of poor quality and/or quantity of health care services or medicines as a reason for not being satisfied with the health care system.

The theme Lack of culturally appropriate services was assigned to quotes where respondents mention of cultural considerations as a reason for their un/satisfaction with the health care system. By cultural considerations we specifically refer to expressed beliefs that certain aspects or practices within the health care system are viewed as inappropriate to Xavante traditions.

The theme Lack of transportation was assigned to quotes where respondents mention of inadequate transportation services as a reason for their un/satisfaction. Specifically, this theme captures complaints of the need to travel far distances to the city to receive health care.
The theme *Attitudes and behaviors of health care workers* was assigned to quotes where respondents mention the inappropriate attitudes or behaviors of the health care workers as a reason for their dis/satisfaction. By attitudes we refer to perceptions of the health care workers’ desire to work in the communities, and how it impacts the function of the health care system. With behaviors we were mainly concerned with experiences at the care of a health worker or specific actions, which may have affected the individual or community. Examples include discrimination or perceptions of apathy towards the Xavante.

The theme *Health system inefficiencies* was assign to quotes where respondents mention events occurring within the health system that would suggest a dysfunction or inefficiency. We were interested specifically in the possible gap in the management and monitoring of population health status, despite the persistent high mortality rates. Also, inefficient practices, such as distribution of faulty medications were of interest under this theme.
Table 5. Content analysis of qualitative interview transcripts broken down by type of respondent

<table>
<thead>
<tr>
<th>Total respondents (n=30)</th>
<th>Attitudes of Health Workers</th>
<th>Health system inefficiencies</th>
<th>Lack of culturally appropriate services</th>
<th>Lack of medication or health care services</th>
<th>Lack of transportation</th>
<th>Social Determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chief’s speech (n=4)</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Health Care Worker (n=2)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>EDS patients (n=6)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Questionnaire (n=23)</td>
<td>10</td>
<td>6</td>
<td>3</td>
<td>16</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>10</td>
<td>5</td>
<td>23</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>
4. Discussion

4.1 Health seeking behaviors and experiences

This study provides a novel contribution to the field of indigenous health in Brazil. The study addressed socioeconomic determinants of care use and perceived barriers. A sample of 50 individuals selected at random from Expedicionários da Saúde’s patient listing participated in the survey portion of this study before receiving outreach care. The age range of the participants spanned 20 to 90 years of age. Just under half of them reported to have visited a health clinic within the last year (18/50). Surprisingly, a majority never received care from a health clinic (24/50). Age did not seem to be associated with the timeliness of seeking health care (figure of cross tab age and recent visit). Some never felt in need of health care, while others chose not to use care because of a preference for traditional medicine, or reservations against biomedicine. Among the 26 individuals that did receive care previously, the main types of health concerns include: injury-related, acute concern, musculoskeletal, surgical related, obstetric, chronic disease, or physical exam. The most common musculoskeletal complaint was knee problems.

Interview participants explained the process of seeking health care and the associated challenges. Sick individuals are encouraged to go to the Polo Base (health clinic in village or another village close by if it is not located in their own village), however some individuals decide to go right to the hospital, or stay within their village and use their own treatments. A number of issues were reported with each option. If a sick individual first seeks care from the Polo Base clinic and the attending nurse believes that they are in need of higher-level care then they are driven to the hospital by a government worker. However, individuals who live in villages where there is no Polo
Base are required to travel to the village where it is located. The individuals seeking care directly from the hospital complained of the long waiting times often experienced in the hospital. Some individuals choosing to stay in the village expressed having chosen to do so out of disbelief that the health care system would be helpful. We also asked each participant about their satisfaction with health care in their community and in Brazil in general. Unsurprisingly, the majority of respondents were unsatisfied with the health care in their community (30/50) and with the health care situation in Brazil in general (33/49).

4.2 Barriers to care

Here we describe five barriers to receiving health care within the Xavante communities studied.

4.2.1 Lack of transportation

Due to the remoteness of most indigenous villages, traveling to receive health care services is an arduous task; Indigenous individuals must overcome significant geographic barriers to access care. Recognizing this barrier, in theory the government provides transportation for patients in need of higher-level care. In practice, however, access to transportation services is inequitable and the availability of services is unreliable.

We observed these challenges within the Xavante population. As seen in Table 3, under a third (14/50) of survey respondents reported being unable to receive healthcare when needed; of which a lack of transportation was the most frequently reported reason why (8/14). Similarly, some of the interviewed individuals discussed
inconveniences they experienced with the transportation network (8/37). As described by the interviewed participants, government transport did not always show up to the villages to transport patients. As a result some patients were left to find their own means of getting to the Polo Base – one of our participants described one instance of sending a patient in the community’s car to the city to receive care in the hospital.

Access to health care differs within indigenous territories, which promotes regional health inequalities. A key characteristic of most Amazonian indigenous communities is the diversity in the location of the various villages contained within the territory. The indigenous health care system is based on a districting model of health service delivery – indigenous territories are broken down into “districts” that each contain a single health post to serve the surrounding villages. However, location from health post is considered a determinant of access to care. In villages where there is a fully staffed health post, individuals can easily access care and therefore end up utilizing it more frequently (Grenfell et al., 2008). Further, poor access to health care is associated with worse health outcomes (Buitrón, Hurtig, & San Sebastián, 2004). On our tour of three Xavante territories, we found only two villages that had fully staffed health posts.

4.2.2 Lack of health care services or medicines

Just reaching the health clinic does not always guarantee care, as Indigenous patients may not receive the health care services or medications to address specific health needs. In our study, almost every participant in both the quantitative survey and qualitative interviews complained about the lack of health care services or medicines. Of the 26 survey respondents that previously received care, only nine individuals reported being unsatisfied with the visit. However, when asked to reflect on that visit and to
select potential reasons from our survey for being unsatisfied, the most frequently reported issues were "felt the provider's drugs or equipment was inadequate" (6/9) and "felt the provider's skills were inadequate" (5/9). Further, lack of health care services or medication was mentioned in over half of the interviews (24/37). Some participants accredited the worsening health situation to the use of generic medicines in place of branded formulations; however, the greatest concern was simply an overall lack of medication. Two of the four chiefs interviewed specifically stated that their village health post frequently experienced medication stock-outs. Interestingly, individuals reported being satisfied with the health care staff at the village Polo Base clinic; instead they recognized the challenges the health workers faced trying to provide care with resource shortages (see Panel 1. for more information on DSEIs). Seeking care at the hospital was also perceived as a significant issue. Individuals complained of experiencing long wait times while trying to receive care at the closest urban center hospital. Often it would take a number of visits to eventually receive the treatment that the individual needed. The first visit to the hospital is usually just a consultation to book another appointment, requiring the patient to travel many times between the village and city. Besides the stress of the frequent traveling, caregivers spend extended periods of time spent away from home, meaning that fewer individuals are around to feed the rest of the family.
Panel 1. The Indigenous Health Care System under the Ministry of Health (SESAI) and the role of DSEIs

The Indigenous sub-health system:

The district model of health care embraces the Ministry of Health’s mission to provide regionally specific care and to foster local participation in care. The current Indigenous sub-health care system is organized into 34 special Indigenous Health Districts (DSEI). Each district provides health care services and acts as a referral network to a catchment population of socioculturally related indigenous territories. DSEIs are considered as autonomous units, responsible for service provision and surveillance. DSEIs receive support from and function under the policies created by the Ministry of Health.

Human resources for Health:

Each DSEI has a number of multidisciplinary indigenous health teams (EMSI). EMSIs are made up of village indigenous health workers (AiS), who are supported by nurses, a dentist, and nursing auxiliary working out of a regional Polo Base. DSEIs are managed by district head with support from a team of health professionals and specialists. Finally, a District Indigenous Health Council (CONDISI), made up of DSEI managers, health professionals and local indigenous representatives, provide oversight to planning and performance functions of the DSEI. Indigenous representatives make up 50% of CONDISI and are elected by local indigenous communities.

DSEI functions:

DSEIs are responsible for surveillance and data collection, in addition to provision of primary health care services. Indigenous health care workers collect data on growth monitoring, birth/death recording and epidemiological surveillance activities using equipment provided by UNICEF and SESAI. The data are recorded on paper in notebooks and/or on printed forms. EMSI professionals supervise data collection by the Indigenous health workers through frequent village visits. Data are passed on to EMSI who must then transfer data into an electronic database (Excel sheet) at the respective Polo Base. Frequent village visits provide opportunities for EMSI to meet with local indigenous health councils, which consist of indigenous leaders from that area, engaging in situational analysis and planning meetings; here, they identify causes of nutritional vulnerability and other health issues, and plan quick responses. Data is then passed from EMSI to managers at DSEI headquarters who are supposed to upload data to SIASI database for insertion into the DSEI-level aggregate spreadsheet for SISVAN-I monitoring system (nutrition monitoring system). Analysis of data from each polo base should allow DSEI managers to identify specific priorities for immediate and long-term response for each polo base. DSEI managers responsible for using data to put together three-year district plans and annual implementation plans, and set budgets in agreement with CONDISI, allowing for local participation. Data are sent to SESAI managers, responsible for coordinating DSEI-based health and nutrition services in Brasilia.

(Shankland, Toledo, Barbosa, & Bittencourt, 2013)
4.2.3 Attitudes of health care workers or government

The function of any health system is dependent on the performance of its health care workers. In low and middle-income countries, poor health care worker performance contributes to low rates of health care use (Rowe et al., 2005). Given the high burden of disease and inconsistent availability of health care, indigenous patients form negative perceptions of the ability of health care workers to address their health needs.

While we did not directly study health care worker performance, we were interested in understanding how indigenous perspectives of the health care workers manifested in health care seeking behavior. Just over a third of the individuals we surveyed mentioned having avoided seeking care in the past. For a majority of these individuals, the most dissuasive factor was having bad experience being treated (9/16) and/or disbelief in the ability of the provider to help them (11/16). The attitude of the health care workers/government was the second most frequently discussed issue in the interviews (16/37). Most interview respondents spoke negatively of the government and the health care workers, and rather felt that there is an underlying culture of discrimination against indigenous people. A number of respondents reported having experienced some form of discrimination with health care. Chiefs felt discriminated against by policy makers. Individuals mentioned experiencing a lack of service as a result of discrimination.

4.2.4 Lack of culturally competent services

Intercultural differences between the Xavante and health care providers form another barrier to receiving care. In interviews with Xavante patients and local
health care providers, each identified different challenges they experienced. One Xavante individual felt that the health care workers did not provide resources for culturally appropriate burial practices. For health care workers, Xavante cultural practices complicated treatment; patients often would not take their medications on time; children were not always bathed and fed nutritious meals.

We assert that poor cross-cultural communication explains these misunderstandings between indigenous patients and non-indigenous providers. The Xavante we interviewed subscribed to the notion that the health care workers did not understand indigenous health. Previous studies on the implementation of the current indigenous health system in Brazil highlight a number of problems with the training and management of health care workers. Diehl and Pellegrini accuse SESAI of failing to acknowledge socio-cultural specificities, criticizing their method of providing “full attention” instead of “special attention”. They recommend that health care workers receive continuing education in language and cultural training giving them a necessary understanding of the communities they work in from a social perspective (Eliana Elisabeth Diehl & Pellegrini, 2014).

4.2.5 Social Determinants of Health

The social determinants of health are all factors outside of the health care system, which are believed to have an impact on health. Of the five themes, this was least recognized by interviewed participants (4/37). It is important to note that half of the chiefs (2/4) and one of the two health care workers discussed this issue in detail. The widespread incorporation of industrialized foods into the Xavante peoples’ diet is believed to have been responsible for the rapid rise in cases of diabetes, as well as issues
of alcohol abuse (C. E. Coimbra Jr et al., 2004). In addition certain lifestyle changes have contributed significantly to the rise in obesity and non-communicable disease. A number of case studies of different indigenous communities have demonstrated an association between the emergence of obesity and non-communicable disease with commoditization of indigenous economies, transition to a more western diet, and the reduction of physical activity (C. Coimbra, Santos, Salzano, & Hurtado, 2004). While not investigated in this study it is also important to consider socioeconomic differentiation within communities. Recently it has been demonstrated that wealth is associated with measures of obesity (Welch et al., 2009).

The Xavante are not naïve to the impacts of poor diet on their health; they just do not know what to do about it. Indigenous communities worldwide deal with the same struggle when it comes to food security. Modernization and lifestyle changes, changing environmental factors affecting food quality, and social factors dictating access to certain types of food, all exacerbate inequalities in nutrition (Kuhnlein et al., 2006). With the limited research available on this subject, we know that interventions must involve and empower the community, embrace cultural norms, and be locally pragmatic. They also recommend that the process be political (Rudolph & McLachlan, 2013). With a history of legal battles with ranchers and soy producers usurping their traditional lands, the Xavante know political warfare all too well. It is up to them to engage traditional knowledge and empower communities to revert back to traditional diets. However, this does not relieve the government of its commitment to protecting their lands and providing assistance. Finally, as one health worker discussed these changes in health have a genetic component. Since the Xavante were only contacted 60 years ago, their bodies have not been able to adapt to the rapid change in dietary and lifestyle factors
While not as widely recognized, social determinants underlie the poor health status of the Xavante people.

4.3 Implications for policy and practice

Based on our findings we propose three policy recommendations in order to improve indigenous health care:

4.3.1 Improve access to care via communication infrastructure and logistics development

A faulty transportation system impedes easy access to health care services. Vehicles owned and operated by SESAI (the MoH) are stationed at Polo Base health posts and are responsible for bringing patients to the hospital upon referral from the attending physician or nurse on site; however, a majority of villages do not have a health post. In fact, individuals are unable to call to the health post in the case of an emergency as most territories lack cellular service (Shankland, Toledo, Barbosa, & Bittencourt, 2013). Investing in something as simple as two-way radios to be distributed throughout the various territories could help establish a functional communication network, allowing patients in villages without a health post better access to call for help to the SESAI vehicle in the case of an emergency.

A more effective communication network could also help improve inefficiencies in the existing referral chain in order to reduce long waiting times and unnecessary trips off indigenous land, and into the city. Patients sometimes need to commute between their village and the local city many times before receiving care. These trips often span a long period of time and burdensome to families - when a father is away from home the family has difficulty of getting food, or when the mother is away there are fewer people
to take care of the children. Telemedicine has been used as an effective tool for reducing the need for referrals by connecting chronic disease patients in rural communities of Canada and Australia to specialists in urban centers (Wolz S., 2011). Using mobile technology some of the consultations that originally occurred in the city could take place within the indigenous territory, therefore avoiding the need to travel and wait in the city. Infrastructure for a telehealth program already exists in Brazil, however poor implementation and mismanagement of resources halts expansion (Taveira Z. et al., 2014).

4.3.2 Strengthen health data management and information reporting systems

There is a significant information gap of health data for indigenous populations. In Brazil health reporting systems for indigenous populations are weak and inefficient. Two health information systems are currently in operation in Brazil. The first is SISVAN, a database of nutritional and sanitary indicators for all children in Brazil. The second is SIASI, a program that collects and stores health information from indigenous populations. SIASI was designed to collect specific health information organized into separate modules. To date only 3 of 7 modules are functional - population, morbidity and immunization – and a number of other weaknesses have been recognized: dysfunctional collection instruments, human resource training, lack of integration with other national health information systems, poor access to information, and lack of incorporating information for policy making decisions (Sousa Mda, Scatena, & Santos, 2007).
The infrastructure for robust health data collection is already in place, therefore future interventions only need to focus on the logistical inefficiencies that weaken existing systems. In a case study of the Xavante DSEI (see Panel 1.) Shankland describes key leveraging points for improvement. First, a greater focus should be placed on data collection processes. EMSI managers require better supervision to ensure that data is frequently collected by AiS and entered into the electronic database (Shankland, Toledo, Barbosa, & Bittencourt, 2013). This way policy makers will have timely information on the health status of indigenous populations, informing swift actions when necessary.

Another issue is the limited availability of health data to the public. As indigenous health researchers in Brazil have described, overcoming informational gaps is the next step to in order to reduce indigenous health inequalities (C. Coimbra et al., 2004). In 2013, Coimbra et al. published, “The First National Survey of Indigenous Peoples’ Health”, representing the first attempt to systematically collect high quality health data from the National Indigenous population (C. E. Coimbra et al., 2013). By making data more easily available, the government would benefit from potential collaborations with researchers to improve existing health information systems.

4.3.3 Contract with local NGOs to provide specialized care

The Brazilian government should consider establishing public private partnerships with local NGOs to improve health care service delivery in indigenous populations. Contracting agreements allow governments to outsource certain responsibilities for health care to non-governmental entities (can be for-profit or non-profit). Contracts may take on various forms, which will dictate the government’s role in the partnership. With management contracts the government still delivers health care
services, which are then managed by the contracted body. On the other hand, service delivery contracts relieve the government of service provision duties, and instead decide on the services that will be provided, where and how.

A large evidence base exists supporting the effectiveness of contracting out health care service delivery. The most appealing features include: a greater focus on outcomes and measurable results; the lack of bureaucratic technicalities that constraint resource availability; flexibility of private sector and overall higher morale to delivery quality services; greater managerial autonomy and decentralized decision making; competition as a tool to increase effectiveness and efficiency; and liberty for governments to focus on unique roles they are positioned to take on, such as setting and enforcing regulations, financing, and planning within public health institutions (Loevinsohn & Harding, 2005). That said, a number of challenges with contracting have been recognized. These challenges include: large scale feasibility to make an impact at a country wide level; contracts are more expensive than government provided care; contracts could increase existing disparities in access to health care; governments do not possess the capacity to efficiently manage contracts; and contracts are not sustainable.

Contracting has already been used successfully for various purposes in a number of settings. A program in Bangladesh, where the government contracted local NGOs to help expand primary health care services, resulted in the expansion of coverage to the poorest 50% of the population (Heard, Nath, & Loevinsohn, 2013). The care delivered by the NGOs was not only higher quality compared to government services, but also larger gains in coverage were observed in areas served by the contracted NGO. In Guatemala, a similar type of contracting initiative was used to improve primary health care service
delivery in under-served remote rural communities. As a result country-wide coverage for primary health care services has increased to 27% (G. La Forgia, Mintz, & Cerezo, 2004). The possibilities for contracting partnerships are not just restricted to primary health care. Contracting has also been used to improve TB control in India (Murthy, Frieden, Yazdani, & Hreshikesh, 2001) and to combat malnutrition by strengthening community nutrition services in Madagascar and Senegal (Marek, Diallo, Ndiaye, & Rakotosalama, 1999).

In practice certain critiques to the public-private contracting model are not relevant as expected. The success of primary health care initiatives, such as the Guatemala program (G. La Forgia et al., 2004), demonstrates the possibilities of achieving country-wide effects, even in the poorer and remote areas. Contracting programs have also been shown to be much more cost-effective than government services (Loevinsohn, 2014), generating costs as little as 1% of the respective country's gross national income (Loevinsohn & Harding, 2005). The Bangladesh program, already mentioned, serves as an example of the potential to provide equitable services to even the poorest regions (Heard et al., 2013). Also, even where contract management was difficult for the country's government, positive effects from improved service delivery still resulted (Marek et al., 1999). Sustainability however is a real concern. In a review of contracting by Loevinsohn and Harding, seven of the nine programs they studied had been expanded; however, they remain skeptical and call on for more research to be done to answer this question regarding sustainability (Loevinsohn & Harding, 2005).

The Brazilian Ministry of Health has already demonstrated its commitment to building public-private contracting partnerships as a means of improving service
delivery. A number of hospitals in the state of Sao Paulo are run by non-profit operators, which were contracted by the government after it failed in the completion of its ambitious plan to expand and efficiently operate hospital care (G. M. La Forgia & Harding, 2009).

Expedicionários da Saúde is an example of an ideal candidate for the type of public-private partnership we propose. They possess both the resources and commitment to provide medical services to indigenous populations in Brazil. Outreach as a more efficient and culturally appropriate means of providing highly specialized care, as Indigenous do not need to leave their villages and instead receive high quality care (Russell Lindsay Gruen, Weeramanthri, & Bailie, 2002). Using this model a much larger group of people can be treated in a shorter period of time. This reduces number of indigenous seeking care at the hospital, therefore lessening the burden of a larger patient pool on the local public hospitals (R. L. Gruen, Bailie, Wang, Heard, & O’Rourke, 2006).

To be effective the government must work together with Expedicionários da Saúde to establish procedures for motivating outcomes. A set of benchmarks must be set and agreed upon by both parties. Expedicionários da Saúde must start collecting more comprehensive data on outcomes. On the other hand the government should support quality data collection and incorporate existing public health authorities within SESAI and the ministry of health into policy decision-making processes. Finally, the government needs to provide adequate resources, through either in-kind donations or global budgets, to increase the capacity of Expedicionários da Saúde to carry out more frequent expeditions.
Existing collaborations between Expedicionários da Saúde and the Brazilian Government makes this partnership feasible. The mobile hospital center materials are transported to and from remote sites by the Brazilian Airforce. Basic resources, such as fuel for generators are provided by the government as in-kind donations. Expeditions are coordinated with SESAI and local DSEIs, who provide logistical support for patient triaging prior to each expedition, patient transportation to the mobile medical center, and on-the-ground medical support during and after the expedition.

4.4 Implications for further research

Given the tremendous lack of health data on Indigenous populations in Brazil, there should obviously be a greater focus on conducting more research on Indigenous health. Future studies should focus on population determinants of health and utilization issues. Rather than focusing on cultural constructs of health in context of an intervention, future research should address issues with the actual health care system itself. Researchers need to collect data on primary care effectiveness and patient satisfaction with care in other regions as well. This study could be used as foundation for designing future patient satisfaction and primary care evaluation tools specifically for indigenous people. Finally, more research must be conducted on the cost-effectiveness of different health interventions for indigenous populations, as there has only been one study of this kind to date (Carvalho, Benzaken, Peeling, Santos, & Terris-Prestholt, 2011). This will give policy makers more reliable data for funding interventions that will actually work.
4.5 Study strengths and limitations

Our study is the first to investigate barriers to health care in this setting. Previous studies on the Xavante people have focused on population health and demographic changes (Souza et al., 2011). The emerging burden of diabetes and obesity has been widely recognized. Dal Fabbro et al showed alarming rates of diabetes as high as 28.2%, and 50.8% prevalence of obesity. This rate is considered to be much higher than most of the studied indigenous populations in Brazil (Dal Fabbro et al., 2013). Coimbra et. al & Santos et al., chronicle transitions in health of the Xavante over time, in relation the changing environment and the emergence of population needs (C. E. Coimbra Jr et al., 2004; Santos, Coimbra Jr, & Welch, 2013). Other work on the Xavante has investigated the impact of disease specific interventions or cultural constructs related to health care seeking and behaviors (Basta et al., 2010). Yet, to date no studies have evaluated existing models of care from the patient’s perspective. Therefore, this study is unique in that it provides individual perspectives to evaluate the indigenous health care system.

Our goal was to identify barriers to health care, as determined from the indigenous patient perspective. The primary care assessment tool has been used in a number of countries around the world. Its main purpose is to measure the performance of primary care systems. By identifying the strengths and weaknesses of the health care system we can begin to build data for future interventions (Schäfer et al., 2015). Primary health care assessment has already been used in other settings. In Australia it was shown that primary care effectively used, reduced the burden of disease within indigenous communities (Zhao, Thomas, Guthridge, & Wakerman, 2014). We identified barriers specific to indigenous groups, such as cultural incompetency of care.
In other studies of patient satisfaction and primary care assessment in Brazil, such barriers are otherwise unreported (Atkinson & Haran, 2005).

Our sample size was small (n=50) relative to the total Xavante population of 15,000. More men included in the study than women, because Xavante women are less willing to speak with outsiders. Women are important because they are often the ones caring for the children, which means that they have a significant amount of exposure to the health care system; therefore we may have missed out on potentially useful perspectives. Additionally, we only sampled individuals from three of the nine territories. Variations in perspectives across the different territories are recognized within this community. The author was made aware of political conflicts occurring between communities in different territories (Shankland et al., 2013). We did have some difficulty with translating all of the materials. We were unable to translate 7 interviews, which were conducted in the Xavante language due to lost contact with translator after the study. Additionally, we recognize the potential for bias imposed by the field translator. At times certain responses did not match the length of the translation given. However, this was only an issue for four of the interviews as the majority of the interviews were conducted in Portuguese.
5. Conclusion

This study identifies barriers to accessing care in an indigenous Amazonian population. We found that overall there was a poor level of satisfaction with health care. The most commonly reported barriers faced include: lack of transportation, lack of health care services and medicines, attitudes of health care workers/government, lack of culturally appropriate services, and social determinants of poor health. In light of these findings we propose that the Brazilian government invest in developing infrastructure and logistics to improve access to care, improve data collection and management systems of indigenous health indicators, re-integrate FUNAI into health care and focus on prevention, as well as contract NGOs to participate in health care provision to the indigenous. This study may function as a foundation for developing appropriate primary care and patient satisfaction assessments in the future.
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