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**ECONOMIC DISPARITIES  
AND HEALTH**

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# Economic Disparities and Healthcare

Due to differing conditions across the globe, health outcomes and the quality of healthcare can vary greatly between and within different communities. Differences in health education, infrastructure, cultural beliefs, availability of medicine and even access to healthy food and clean drinking water can lead to different treatments and outcomes of serious healthcare issues. Many of these disparities are closely interwoven with the factor of economic disparities between various regions, communities and healthcare systems.

Recent events highlight the effect that economic disparities can have on healthcare. The high death toll of the 25th April earthquake in Nepal has been exacerbated in part by an overstretched hospital infrastructure in the low-income country. In Volume V, Issue I of *The Journal of Global Health*, we discuss a variety of global health issues influenced by the common theme of economic disparity. A lack of access to antibiotics from private vendors, discussed in a paper on neonatal mortality in Nigeria, can worsen illnesses in poor households. One article explores the effects of socioeconomic disparities on health within a single town in India. A third article notes that lower- and middle-income countries have higher maternal mortality rates, partially due to childhood malnourishment and lack of access to antenatal or obstetric care. In each article of this issue, no matter the topic, economic disparities play a subtle or large role in the issues discussed.

Now finishing its fourth year of publication, JGH facilitates dialogue on interdisciplinary global health issues from a variety of academic, cultural and geographic perspectives. By publishing exemplary, student-led research on the subject of economic disparities and health as well as other problems faced by communities all over the world, we hope to shed light on these issues and encourage the next generation of health professionals and policy makers to take active steps towards resolving them. The archived issues of the *Journal of Global Health*, as well as episodes of our podcast, *What is Global Health?*, featuring interviews with a variety of academics, health professionals, and grassroots activists, can be found at [www.ghjournal.org](http://www.ghjournal.org).

## Anjali Doshi Taylor Gray

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## Spousal Age Differences and Risk of Infant Mortality in Nigeria: A Multi-level Analysis

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**Background/objectives:** Nigeria remains the largest contributor to neonatal mortality in Africa. Nigeria's neonatal mortality rate is 48/1000 live births. Existing research on the causes of neonatal mortality in Nigeria has placed great emphasis on factors such as diarrhea, malaria, measles and acute respiratory infections, whooping cough, tuberculosis, bronchopneumonia, dirty feeding bottles and utensils, inadequate disposal of household refuse, poor storage of drinking water and household wealth index<sup>1-4</sup>. However, insufficient attention has been given to parental age-related factors. Understanding the implications of parental age differences for child health can add to our knowledge of the correlates of neonatal mortality and furnish insights to support the design and delivery of interventions to address the problem. To examine the implications of spousal age-related factors for child health outcomes.

**Methods:** Data for this study were drawn from the 2008 Nigeria Demographic and Health Survey. Univariate and multivariate statistical analyses were used to assess the relationship between neonatal mortality and parental age-related contextual factors focusing on maternal and paternal ages, spousal age, sex of child, household wealth index and place of residence.

**Results:** The multivariate logistic regression analyses yielded significantly increased risk of neonatal mortality among neonates of parents with age differences of 15 years or more.

**Conclusions:** Neonates of couples with age differences of less than 15 years die less compared to neonate of spouses with age difference of 15 years and above.

### Introduction

Of the 130 million babies born globally every year, about 4 million die in the first 4 weeks of life, during the neonatal period.<sup>5</sup> Neonatal mortality rate is defined as the number of infants dying before reaching 28 days of life, per 1,000 live births.<sup>6</sup> Most neonatal deaths (99%) occur in low and middle-income countries, with two thirds occurring in Africa and Southeast Asia.<sup>7, 8</sup>

Globally, Nigeria ranks second to India with the highest number of neonatal deaths.<sup>9</sup> Currently in Africa, Nigeria's neonatal mortality rate is the highest of the region at 48/1000 live births with 241,000 neonatal deaths annually.<sup>10</sup> Neonatal mortality rates have declined in most of the developing world, yet remain disturbingly high in Nigeria.<sup>9</sup>

Deaths in the first month of life primarily reflect factors associated with maternal health, both before and during pregnancy, and health problems of the newborn.<sup>11</sup> Deaths in this age range result chiefly from inadequate growth (prematurity, intrauterine growth retardation) and congenital anomalies.<sup>11</sup> As a result, neonatal mortality rates provide an indicator of the factors affecting pregnancy, delivery, the health of the neonate and the adequacy of services in the prenatal, intrapartum and neonatal periods.<sup>12</sup>

Research into the causes of high neonatal mortality in Nigeria has focused on factors such as preterm birth, infections, asphyxia

and low birth weight.<sup>1</sup> Maternal complications in labor, breastfeeding practices, dirty feeding bottles and utensils, inadequate disposal of household refuse, poor storage of drinking water, household wealth index and maternal characteristics are also correlated with neonatal mortality.<sup>2-4</sup> However, few studies have examined the implications of spousal age-related factors for child health outcomes. The few available studies were conducted in developed countries. These studies show that spousal demographic factors, especially age, have huge implications for early child health outcomes. For instance, European studies published between 2002 and 2008 associated advanced paternal age with fetal death, which includes both miscarriage and stillbirth.<sup>13,14</sup> Additionally, a 2002 study in Jerusalem linked paternal age with pre-eclampsia, a complication of pregnancy associated with the development of high blood pressure and protein in the urine.<sup>15, 16</sup>

Significant associations have surfaced between advanced paternal age and childhood conditions such as cleft lip and palate, childhood cancers, congenital heart defects and childhood neuropsychiatric conditions such as autism, schizophrenia, epilepsy and bipolar disorder.<sup>17-19</sup> Paternal age has also been implicated in the etiology of Trisomy 21, Down Syndrome.<sup>20</sup> Other studies found advanced paternal age to be associated with an increased risk of single gene disorders.<sup>21</sup>



Furthermore, the literature shows that the rate of transmitted de novo single nucleotide mutations increases with paternal age.<sup>22</sup> For instance, achondroplasia, the most common form of dwarfism, is a disease in which the probability of having an affected offspring increases exponentially as a function of the father's age.<sup>22</sup> Additionally, the interaction between parental age difference and offspring count in humans has been examined.<sup>23</sup> In such studies, the offspring count for men reached a maximum when the female partner was approximately 6 years younger than the male.<sup>21, 23</sup> The implications of spousal age-related factors for child health outcomes remain an understudied issue in neonatal mortality in Nigeria. According to a 2012 UNICEF report, early childhood health determines the quality of health, well-being, learning and behavior across a person's life span. Early childhood is a period of great development, and with this development comes great vulnerability.<sup>10</sup>

Against this backdrop, this paper examines whether age differences between spouses is associated with neonatal mortality in Nigeria. The similarities or dissimilarities in mortality rates of neonates with regard to differences in their parents' ages are conceptualized and divided into taxonomically and analytically useful categories. Knowledge about these similarities and dissimilarities is linked to the general literature on infant and childhood mortality in Nigeria and the rest of the developing nations.

## Study Design

### *Population*

The data used in this study are from the 2008 Nigeria Demographic and Health Survey (NDHS), the most comprehensive of all the demographic and health surveys conducted in the country. The study was conducted by the National Population Commission (NPC) from June to October 2008, with financial support from the United States Agency for International Development (USAID) and United Nations Fund for Population Activities (UNFPA). ICF Macro International provided technical assistance. Questionnaires were administered on a nationally representative sample of 36,800 households drawn from all 36 states and the Federal Capital Territory.<sup>24</sup> The 2008 NDHS elicited information on demographic and health indicators both at the national and state levels. Data for this study was collected from 33,385 women of reproductive age (15-49 years) who had had at least one live birth in the five years preceding the survey (2003-2008), with a total of 104,808 births. Of these births, 5,665 neonates died.

### *Statistical Analysis*

The outcome variable for this study is neonatal mortality and was measured as the duration of survival since birth in days. The children's survival status and age at death in days (if the child had died), or the last 28 (0-27) days they were known to be alive (if child was still living at the time of the survey), were combined to generate the outcome variable. Neonates known to have died (i.e. non-censored observation) were regarded as the cases, whereas neonates who were still alive at the time of the survey were treated as right-censored. Right censoring occurs when a subject leaves

the study before an event occurs, or the study ends before the event has occurred.<sup>25</sup> The key explanatory variable in this study is spousal age difference, which is categorized as (1) 1-14 year age difference and (2) 15 or more year age difference.

Bivariate associations were used to examine the association between the independent socioeconomic and demographic variables and the dependent variable, spousal age difference. In order to examine such an association, Pearson Chi-squared test assisted in identifying factors that are significantly associated with spousal age difference. The final stage of the analysis was multivariate analysis yielding the odds ratios. The binary logistic regression model was used in this study because the outcome variable is dichotomous or binary: neonatal mortality was coded as 0 (Dead) and 1 (Alive), respectively.

Descriptive statistics calculated in this study included maternal and paternal ages, child's sex, household wealth index and place of residency. For the purpose of this study, maternal age was divided into three age categories: 15-24 (reference group), 25-34 and 35-49 years, while paternal age was divided into four age categories: 15-24 (reference age group), 25-34, 35-44 and 45-64 years. Different age groups were used for males and females because

the mean and median ages of menopause for Nigerian women are  $49 \pm 3$  and 49.0 years, respectively.<sup>26</sup> A new variable, spousal age, was generated by comparing the three maternal age groups with the four paternal age groups. The matching up of these age groups made it possible to study spousal age differences. Rates of neonatal mortality were calculated for each maternal and paternal age group. The adjusted odds ratio along with their 95% confidence

intervals associated with maternal and paternal age groups, with reference to the 15-24 age groups, were derived through unconditional multivariate logistic regression analysis.

Odds ratio (OR) is defined in this study as the measure of association between an exposure and an outcome. It represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure.<sup>27</sup> Paternal age is defined as the age of the father in completed years at the time of delivery.<sup>28</sup> Maternal age is defined as the age of the mother in completed years at the time of delivery.<sup>28</sup> Spousal age difference is defined in this study as the difference between the ages of spouses.

Ages of parents were categorized in order to probe the interaction between different age groups of spouses on child health outcomes. Age gaps of spouses coded "1-14" and "15 and above" years were used to simplify the analysis and interpretation of results and because the author was interested in two possible outcomes (i.e., neonates surviving or dying). The range of 1-14 age difference was used because the mean age difference between spouses in Nigeria is 12.0 years if the wife marries before age 15, compared to 8.5 years if the wife marries at or after age 20.<sup>24</sup> Spousal age differences in Nigeria are even greater when the woman is a second or third wife. In polygynous marriages, the mean age difference between spouses is 15.3 years, compared to 8.8 years in monogamous marriages.<sup>24</sup>

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# The implications of spousal age-related factors for child health outcomes remain an understudied issue in neonatal mortality in Nigeria.

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**Table 1: Bivariate analyses of neonatal mortality and maternal and paternal socio-demographic characteristics**

| Characteristics                  | Outcomes at end of neonatal period (n=104,808) |            |                   |
|----------------------------------|--|------------|-------------------|
|                                  | Deaths (%) (n=5,665)                           | Odds ratio | 95% CI            |
| Maternal age at birth of child * |  |            |                   |
| 15-24                            | 9.54   | 1          |                   |
| 25-34                            | 30.81  | 0.84       | .7632516 .9310423 |
| 35-49                            | 59.65  | 0.95       | .8675274 1.046113 |
| Paternal Age at Birth of child*  |  |            |                   |
| 115-24                           | 9.54   | 1          |                   |
| 25-34                            | 30.81  | 0.84       | .7632515 .9310425 |
| 35-44                            | 37.98  | 0.91       | .8264131 1.00369  |
| 45-64                            | 21.67  | 1.1        | .9335352 1.150172 |
| Child's Sex*                     |  |            |                   |
| Male                             | 57.37  | 1          |                   |
| Female                           | 42.63  | 0.79       | .7314063 .8150122 |
| Parental Age Difference*         |  |            |                   |
| 1-14                             | 13.99  | 1          |                   |
| 15-Abov                          | 17.33  | 2.3        | .0966805 .410784  |
| Household wealth Index*          |  |            |                   |
| Poor                             | 30.16  | 1          |                   |
| Moderate                         | 47.87  | 0.90       | .9055806 1.025992 |
| Rich                             | 21.97  | 0.70       | .6449142 .7492019 |
| Region of Residence              |  |            |                   |
| Urban                            | 4.48   | 1          |                   |
| Rural                            | 5.72   | 1.3        | .1907969 .3217599 |

Source: Calculated from the 2008 Nigeria Demographic and Health Survey

**Table 2: Adjusted odds ratios from logistic regression of neonatal mortality and spousal demographic factors.**

| Characteristics           | Neonatal Births (104,808) |                   |
|---------------------------|---------------------------|-------------------|
|                           | Odds ratio                | 95% CI            |
| Maternal age at birth***  |                           |                   |
| 15-24                     | 1                         |                   |
| 25-34                     | 0.84                      | .2701677 .0714504 |
| 35-49                     | 0.95                      | .4285714 .8472978 |
| Paternal Age at Birth***  |                           |                   |
| 15-24                     | 1                         |                   |
| 25-34                     | 0.75                      | .2701677 .0714504 |
| 35-44                     | 0.89                      | .2012994 .0568129 |
| 45-64                     | 0.96                      | .0687766 .1399118 |
| Child's Sex***            |                           |                   |
| Male                      | 1                         |                   |
| Female                    | 90                        | .8784612 .9367374 |
| Spousal Age Difference*** |                           |                   |
| 1-14                      | 1                         |                   |
| 15-Above                  | 1.4                       | .5384616 .6190392 |

Source: Calculated from the 2008 Nigeria Demographic and Health Survey

**Results**

In the bivariate analysis of neonatal mortality and demographic variables at the individual level, neonates of women aged 35-49 or older were 95% more likely to die compared to those of women aged 15-24 (Table 1). With regard to paternal age, 37.98% of neonatal deaths were correlated with men who were between 35-44 years old (Table 1). Mortality among neonates was more prevalent among spouses with age differences of 15 years and above (Table 1). Male neonates had a higher rate of mortality at 57.37% compared to 42.63% among female neonates. The odds ratio for death among girls was 0.79 (95% CI .73140 - .81501) (Table 1). Spouses living in rural areas were 1.3 times more likely to experience neona-

tal mortality compared with their urban counterparts (OR, 1.3, CI: .19079-.32175). With regard to household wealth index, neonatal mortality was highest among parents of moderate households (Table 1).

Logistic regression analysis showed that sex of child, spousal age difference and maternal and paternal ages were significantly associated with neonatal mortality. Female children were less likely to die as neonates compared to male children (Table 2). Spouses with age difference above 15 years were more likely to experience neonatal mortality compared to those of the reference group category (OR. 1.4, 95% CI 0.539-0.619). Older mothers (35-45) were more likely to experience mortality among neonates compared to younger mothers (OR. 0.95, 95% CI 0.429- 0.847) (Table 2).

**Discussion**

The findings of the study showed a clear effect of maternal and paternal ages on the risk of neonatal mortality. This finding suggests that older women may be at increased risk of neonatal mortality due to common diseases associated with older age, such as diabetes, hypertension and complications of pregnancy, such as abruption. This finding supports the research findings of Astolfi et al., who found that the risk of infant mortality was high in older women (35 years and above).<sup>29</sup>

Neonates born in rural areas were also more likely to die than their urban counterparts (OR, 1.3, CI: 0.19079-0.31275). This supports Izugbara's argument that cities and towns tend to have lower mortality rates than rural areas, possibly because people residing in rural areas are less educated than their urban counterparts, and the distribution of amenities favors the urban areas.<sup>2</sup> Increasing access to drinkable water in rural areas and facilitating access to health-care services to members of rural communities could reduce risks of neonatal mortality. An increased availability and access to drinkable water within the community could prevent children from contracting avoidable infections and water-borne diseases, such as diarrhea and other forms of infections. This study points to the importance of good infrastructure for child survival. This result has established an elevated risk of neonatal mortality for communities in poor socio-economic contexts. The findings also establish one of the reasons rural areas tend to have poorer child health outcomes than their urban counterparts.

Wealth index covariate is another important determinant of infant and child mortality that is established in this study. Spouses of the moderate wealth quintile reported the highest rate of neonatal mortality (Table 2). This corroborates previous findings by Omariba and Boyle, which established that socio-economic factors such as education, occupation and wealth index are more important in infancy than childhood.<sup>30</sup> Yaya et al.'s study of maternal and neonatal mortality in rural Ethiopia also found similar evidence.<sup>31</sup> This study found that the greatest risk for both neonatal mortality and stillbirth was found in the richest households, not the poorest. On the other hand, Uthman found a higher incidence of malnutrition, and thus of morbidity and mortality, among children of a low wealth quintile than among children of the wealthiest quintile.<sup>32</sup> This result was due to many factors, including lack of economic access to antibiotics and other drugs from

private vendors among poorer families. Wealthy families often have better access to these resources, in addition to better nutrition and improved housing. The finding of families of moderate wealth in Nigeria reporting the highest rate of neonatal mortality needs further investigation. It is important to understand how the true wealth status can be determined in Nigeria, since it is possible that the asset variables selected to indicate wealth status may not have correctly reflected the actual wealth status of all households.

Additionally, the data shows that the child's sex is an important predictor of neonatal mortality. Male neonates had higher rates of mortality compared with female neonates (Male, 57.37%, Female, 42.63%, Table 2). This finding also supports research findings of Wells.<sup>33</sup> The survival advantage of girls over boys may be attributed to a higher vulnerability to infectious disease among boys.<sup>34</sup> Another possible reason for the low rate of neonatal deaths among girls may be a result of the development of better early fetal lung maturity in the first week of life, resulting in a lower incidence of respiratory diseases in female neonates compared with male neonates.<sup>35</sup> Globally, it is estimated that approximately 23% of newborn deaths are attributed to respiratory problems.<sup>36</sup> Finally, there was a significant increase in the risk of neonatal mortality if the couple's age difference was above 15 years (Table 2).

## Conclusion

Results from the logistic regression model showed that spousal age gaps, sex of child, maternal and paternal ages were statistically associated with neonatal mortality in Nigeria. The findings of this study have expanded on earlier research that implicated malnutrition, infection, dehydration and diarrhea in neonates in Nigeria. As the rate of neonatal mortality remains high in Nigeria, this may not be resolved until spousal age-related measures and household-focused interventions are implemented. Spouses with age gaps of 15 years and above should be encouraged to seek medical attention whenever the need arises in their neonates.

Discouraging marriages of spouses with age gaps of 15 years and above through effective family planning programs also needs to be considered among neonatal survival interventions because neonatal survival is related to the parents' ages through both genetics and behaviour. Parents pass on genetic material that either serves to improve or worsen their infant's survival. Finally, the

finding of this study may be unique to Nigeria and may not necessarily be generalizable to other countries or populations. There is need for further studies, especially in newer datasets and across other countries, to confirm the findings of this research.

## Study Limitation

Generally, mortality studies are faced with data limitations. The study draws on a cross-sectional secondary dataset. As a result, there is a tendency for child deaths to be underreported. Mothers may be reluctant to talk about their dead children either because it brings back sad memories or because their culture discourages mention of the dead.<sup>2</sup> However, recall errors arising from dates of birth and death given by women interviewed in the survey were minimized by restricting the analyses to births within the 5-year period preceding the survey. Finally, the proportion of missing data was relatively small, such that it may not have influenced findings of this study.

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## A Needs Assessment of Charnia, Haryana in Rural India Reveals Significant Socioeconomic and Health Disparities in a Local Geographical Area

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**Objectives:** The authors of this study conducted a needs assessment in rural Haryana, India to compare health-related perceptions and practices between two populations in the same location: migrant brick laborers (BL) and rural non-brick laborers (NBL).

**Methods:** Data was collected from interviews with 187 households, which were randomly conducted within the Charnia village and three adjacent villages. The survey used in the interview addressed demographics, education, income indicators, hygiene, general health and access to care and reproductive health.

**Results:** Sixty-six (35%) respondents classified themselves as BL, 102 (55%) as NBL and 19 (10%) did not provide a classification. Most (76%) BL and 41% of NBL reported having no education. Symptoms of illness such as cough, cold and fever were significantly higher in BL children under eight years old.

**Conclusions:** Socioeconomic, health and educational disparities exist within the same geographic location, as demonstrated by the significant differences between Charnia's BL and NBL, who reside in close proximity. As the BL population is mostly migratory, BL are unable to fully utilize local health and education infrastructure. Targeted health education programs designed to take place during the brick manufacturing season could help BL understand the consequences of any symptoms they may have, prevent chronic and infectious disease and improve the accuracy of self-reported data. Therefore, disparities must be targeted through a community-based approach that recognizes and addresses the varying population dynamics of BL and NBL in Charnia. Overall, health interventions in rural India must consider the characteristics of diverse population sub-groups in order to be effective and sustainable.

### Introduction

Despite ongoing progress, widespread poverty persists in India, with 29.5% of the population living below the poverty line.<sup>1</sup> The World Health Organization (WHO) Southeast Asia region, which includes India, bears 40% of the global poor.<sup>2,3</sup> Poverty is especially prevalent in rural areas, where 77% of the Indian poor reside.<sup>4</sup> Social factors such as gender, literacy and disparities in land ownership exacerbate poverty in rural India; females, illiterate individuals and unskilled laborers are at a higher risk for poverty.<sup>4</sup> Studies in different countries have shown a strong association between poverty and ill health, the latter of which perpetuates the cycle of poverty.<sup>5,6</sup> Within a single community, groups with differing education levels and employment statuses may have varying health outcomes.

Household needs assessments can increase knowledge of current health standards and living conditions within a community. Therefore, needs assessments can be used to understand the community's level of health, literacy and perceptions of its own health problems.<sup>7</sup> This information can, in turn, influence policies to minimize health disparities and enhance healthcare infrastructure.<sup>8</sup>

We conducted a needs assessment in the area of Charnia, Haryana, to identify similarities and differences in health-related perceptions and practices between two different populations living in the same geographic location: migrant brick laborers (BL) and non-brick laborers (NBL). The Charnia area is unique in that it contains these two populations within the same geographical area. The overall goal of the needs assessment was not to compare and contrast the



**Figure 1** Overview picture of Charnia village.

health practices of people of two different vocations (BL and NBL), but rather the different residence patterns of the two groups. BL are largely migrant workers who travel from Uttar Pradesh and Bihar to Charnia to work at the brick factory and later leave Charnia to return to their homes at the end of the monsoon season. The NBL population is a more permanent population that resides in Charnia year-round. Therefore, the Charnia area is unique in that it offers the opportunity to compare a migrant population subgroup with a stationary subgroup in one specific location. Through this study we hoped to supplement the literature with an analysis of disparities between two different subpopulations living in geographic proximity and to better understand how to design interventions targeting these communities. To our knowledge, this study is the first needs assessment of its kind in the region.

## Methods

### *Population*

Charnia is a rural area in the North Indian state of Haryana (Figure 1), which has a population of 25 million. The Charnia region itself has a population of 13,600 people. The region includes the village of Charnia (population: 2,600) as well as several geographically proximal villages such as Kiritpur, Kherawali and Karanpor.<sup>9</sup> The study groups were BL living in informal settlements surrounding the brick factories, known as “brick zones”, of 50-100 laborers and NBL living in permanent villages. These groups were chosen because they live in the same geographical area (Figure 2).

### *Survey Development*

We designed a survey using the WHO model for needs assessment.<sup>10</sup> The survey included questions on education, literacy, family



**Figure 2** Overview picture of a brick laborer community.

demographics, material possessions, access to healthcare facilities, income stability, access to food and clean water, sanitation and hygiene, general health of self and family members, chronic and infectious disease prevalence, immunizations, trauma, injury, wound care and reproductive health (Appendix 1). The needs assessment was exempt from the Northwestern University Institutional Review Board.

### *Sampling Selection and Data Collection*

Data was collected from August 19 to September 6, 2012 through household-level interviews. Households were classified into two strata: BL and NBL. Within each stratum, households within the Charnia village and three adjacent villages, Kiritpur,

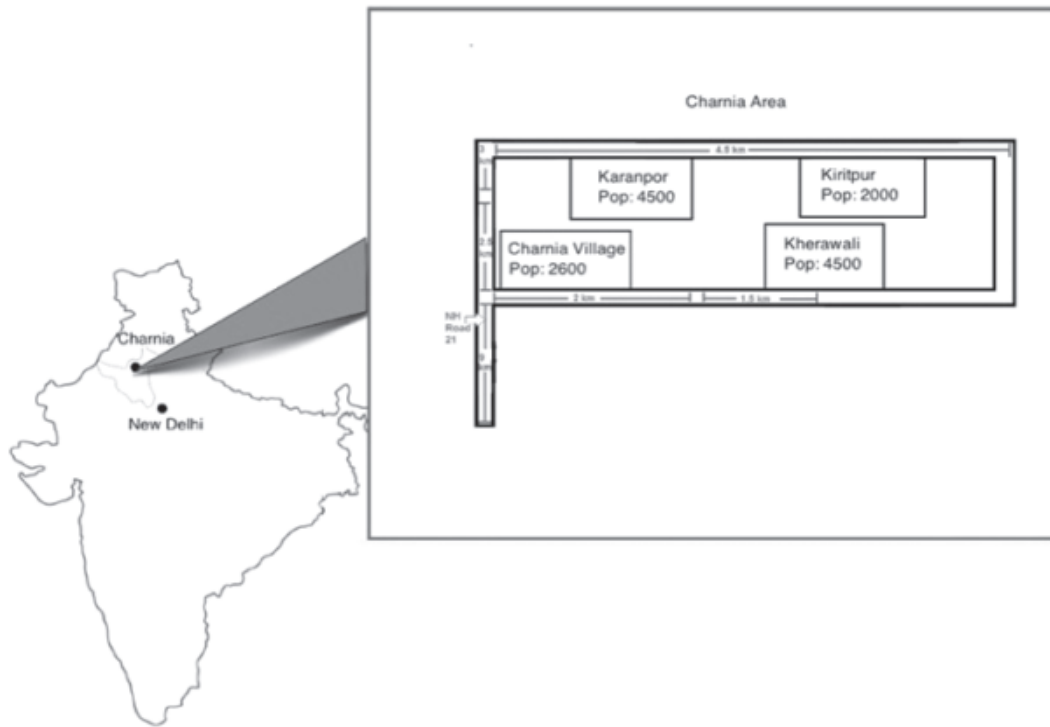


Figure 3 Map of the Charnia village and surrounding areas surveyed. The entire region surveyed shall be referred to as Charnia.



Figure 6 Picture of tube well.

Univariate analysis of categorical data between labor groups was conducted via Fisher's exact test and within groups via the one sample chi-square test. Univariate associations between groups of count data were reported as means and 95% confidence intervals (CI). Multivariate analyses involved Poisson regression when the response was count data and logistic regression when the response was binary. Least-square means and standard errors were obtained from Poisson regression; odds ratios and their 95% CI were reported from logistic regression analyses, where standard errors and CI were presented as measures of variation.

The relationship between the number of children in school and population type was determined by regressing the number of girls and boys in school on population type while controlling for chil-

Kherawali and Karanpor, were then randomly sampled. These three villages, which were closest to the Charnia village, were included to obtain a larger sample size within the same geographical region. The entire region surveyed shall be referred to as Charnia (Figure 3).

Surveys were administered by a pair of surveyors: a speaker fluent in Hindi and a recorder to transcribe in English. Assessments were conducted in Hindi after obtaining verbal consent, and queries were directed to the primary caregiver in the household. Responses were transcribed onto a standard data collection form. For the culturally sensitive portions of the survey, including portions regarding reproductive and sexual health, the surveyor spoke with the individual in private.

#### *Data Management and Analysis*

Data was entered into a Microsoft Access 2010 (Microsoft Corporation, Redmond, Washington) database. Due to the small BL sample size, differences between the BL and NBL population of 15-20% could be detected at the 5% significance level with 80% power. Pearson Chi-Square analysis was conducted using SPSS Version 21 (IBM Corporation, Endicott, New York) to determine statistical differences in response to proportions between BL and NBL populations. Poisson and logistic regression analyses were conducted in SAS v9.4 (SAS Institute, Cary, North Carolina).

dren under five in the household, total number of children in the household and years of the parent's education.

Logistic regressions were carried out to determine the effect of availability of electricity and population type on the ownership of television, refrigerator and mobile phones while controlling for self-reported income variability. In order to isolate the effect of the number of years of education and respondent group on the number of children per family, a Poisson regression was applied. The status of BL was treated as a dummy variable; age and gender were controls. Using Poisson regression, the prevalence of diarrhea in children under eight years of age was regressed on respondent type. The researchers controlled for the total number of children in the household and number of years of education of the surveyed parent.



Table 1. Demographic characteristics of households surveyed in Charnia area, Haryana – 2012.

| Demographic Characteristic        | Total (%) N=187 | BL (%)<br>n=66 | NBL (%)<br>n=102 | P-Value |
|-----------------------------------|-----------------|----------------|------------------|---------|
| Female                            | 122(65.2)       | -              | -                | -       |
| Male                              | 65(34.8)        | -              | -                | -       |
| No Education                      | 92(57.5)        | 50(75.8)       | 42(41.2)         | <0.0001 |
| Completed Secondary Education     | 30(16.8)        | 9(11.5)        | 21(19.3)         | 0.03    |
| Hindi/ Punjabi Literacy (Reading) | 82(43.9)        | 21(31.8)       | 50(49.0)         | 0.04    |
| Hindi/Punjabi Literacy (Writing)  | 79(42.3)        | 21(31.8)       | 48(47.1)         | 0.09    |

Table 2. Permanent income indicators of households surveyed in Charnia area, Haryana - 2012.

| Material Possession | Total (%)<br>N=187 | Brick Laborer (%) n =66 | Non-Brick Laborer(%) n=102 | P-Value |
|---------------------|--------------------|-------------------------|----------------------------|---------|
| Stove               | 92 (49.1)          | 19 (28.8)               | 60 (58.8)                  | <0.001  |
| Refrigerator        | 80 (42.8)          | 10 (15.2)               | 61 (59.8)                  | <0.001  |
| Television          | 144 (77.0)         | 43 (65.2)               | 84 (82.4)                  | 0.048   |
| Mobile phones       | 145(77.5)          | 49 (74.2)               | 80 (78.4)                  | 0.85    |

Table 3. General health characteristics of households surveyed in Charnia area, Haryana - 2012.

| Characteristic (at least one occurrence) | Total (%)<br>N=187 | BL (%)<br>n=66 | NBL (%)<br>n=102 | P-Value |
|--|--------------------|----------------|------------------|---------|
| Anemia                                   | 45 (24.1)          | 10 (15.5)      | 30 (29.4)        | 0.04    |
| Hypertension                             | 60 (32.1)          | 13 (19.7)      | 38 (37.3)        | 0.053   |
| Typhoid Fever                            | 44 (23.5)          | 21 (31.8)      | 19 (18.6)        | 0.09    |
| Hypotension                              | 34 (18.2)          | 7 (10.6)       | 21 (20.6)        | 0.13    |
| Malaria                                  | 27(14.4)           | 14 (21.2)      | 12 (11.8)        | 0.13    |
| Smoking                                  | 46 (24.6)          | 23 (34.9)      | 20 (19.6)        | 0.16    |

Table 4. Reproductive health characteristics of households surveyed in Charnia area, Haryana - 2012.

| Reproductive Health                   | Total (%)<br>N = 187 | BL (%)<br>n=66 | NBL (%)<br>n=102 | P-Value |
|---------------------------------------|----------------------|----------------|------------------|---------|
| Midwife delivery at home              | 70 (37.4)            | 34 (51.5)      | 34 (33.3)        | 0.005   |
| Hospital delivery                     | 56 (30.0)            | 12 (18.2)      | 37 (36.3)        | 0.004   |
| Iron supplementation during pregnancy | 51 (27.3)            | 12 (18.2)      | 34 (33.3)        | 0.02    |
| Regular periods                       | 75 (40.1)            | 22 (33.3)      | 45 (44.2)        | 0.01    |
| Cloth usage during menstruation       | 67 (35.8)            | 27 (40.9)      | 34 (33.3)        | 0.78    |

## Results

### Demographics and Education

One hundred and eighty-seven household-level interviews were conducted. The survey was administered to the individual in the household who obtained the water, cared for the children and assisted any sick family members; 122 (65%) respondents were female, 65 (35%) respondents were male and the median age of respondents was 35 (range 17-80 years). Sixty-six (35%) respondents classified themselves as BL, 102 (55%) as NBL and 19 (10%) did not identify with either group. Of NBL, 25% stated they were farmers (Table 1; Figure 4).

Most (76%) BL reported no education, as compared to 41% of NBL ( $p<0.0001$ ). There was no statistically significant difference in primary education between BLs and NBLs; however, 12% of BL received a secondary education (10<sup>th</sup> grade, 12<sup>th</sup> grade and BA levels) as compared to 27% of NBL ( $p=0.03$ ). Of BL respondents, 33%

reported Hindi or Punjabi literacy versus 49% of NBL ( $p=0.04$ ).

Female BL reported fewer years of education than NBL females (a 95% CI = [0.575, 3.07] for BL women versus [4.42, 7.06] for NBL women). Similarly, male BL had fewer years of education than male NBL (a 95% CI = [0.910, 5.17] for BL men vs. [3.12, 8.05] for NBL men).

Controlling for age and gender, BL had a significantly higher average number of children than NBL (2.0 vs. 2.8,  $p = 0.002$ ). Education rates of children (dependents under 18 years) differed between groups. 51 (39%) BL male children were in school compared to 80 (61%) NBL male children ( $p=0.01$ ); twenty-eight (33%) BL female children were in school compared to 56 (67%) NBL female children ( $p=0.002$ ).

### Permanent Income Indicators

BL were less likely to own stoves ( $p<0.001$ ), refrigerators ( $p<0.001$ ) and televisions ( $p=0.048$ ). Both BL and NBL had simi-

lar access to mobile phones, with 80% of all households owning at least one mobile phone (p=0.85) (Table 2; Figure 5).

In both groups, the availability of electricity was associated with an increase in odds of owning a refrigerator (Odds Ratio (OR) and 95% CI: 11.02, 1.27-95.58, p=0.03) and with an increase in odds of owning a television (OR and 95% CI: 11.98, 2.46-57.40, p=0.002). Adjusting for electricity and fixed income, BL were significantly less likely to own a refrigerator (OR and 95% CI: 0.11, 0.05-0.27, p<0.0001) or television (OR and 95% CI: 0.30, 0.12-0.76, p=0.01) than NBL. However, no statistically significant difference was found between groups for the availability of electricity in correlation with the possession of mobile phones.

**Sanitation and hygiene**

No significant difference was found in sanitary or hygienic practices between BL and NBL. Teeth brushing and hand washing were found to be similarly prevalent in both groups. However, significantly fewer BL showered daily (33% vs. 57%, p=0.02). In addition, sources of drinking water differed between the two groups. The primary source of drinking water for NBL was municipal tap water (70%), while only 17% of BL had access to tap water (p<0.0001) (Figure 6).

*General Health and Access to Care*

While chronic disease rates were high in both groups, self-reported rates of anemia and hypertension were higher in NBL. Of all respondents, 24% reported that at least one household member suffered from anemia, 32% from hypertension and 18% from hypotension. Self-reported rates of anemia (16% vs. 29%, p=0.04) and hypertension (20% vs. 37%, p=0.053) were lower in BL.

No significant differences were found for self-reported disease rates of tetanus or tuberculosis between the two groups. Of all respondents, 24% reported at least one household member suffered from typhoid fever. Self-reported malaria rates were higher among BL (21%) compared with NBL (12%) (p=0.13).

Thirty-five percent of BL and 20% of NBL reported smoking unfiltered cigarettes (p=0.16) (Table 3; Figure 7).

Common symptoms of illness in children younger than eight years (such as cough, cold and fever) were significantly higher in BL (6.0 ± 0.3 in BL vs. 4.5 ± 0.3 in NBL, p = 0.001). For frequency of diarrhea in children under eight years of age, a positive, albeit insignificant, effect of BL status was observed (1.49 + 0.18 in BL vs. 1.14 + 0.15 in NBL, p = 0.15). The level of education of the parents had a significant impact on the prevalence of diarrhea

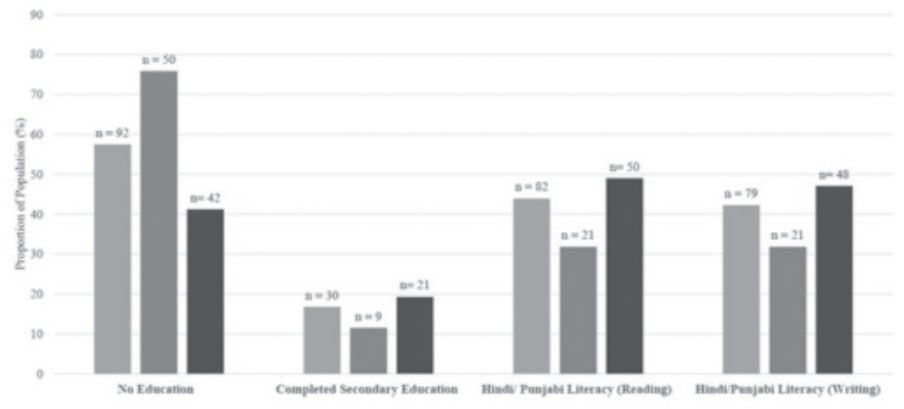


Figure 4. Demographic characteristics of households surveyed in Charnia area, Haryana – 2012.

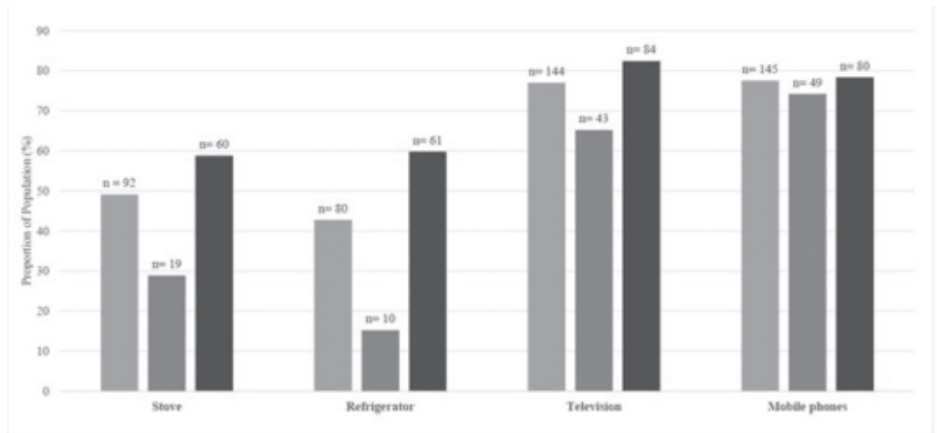


Figure 5. Permanent income indicators of households surveyed in Charnia area, Haryana - 2012.

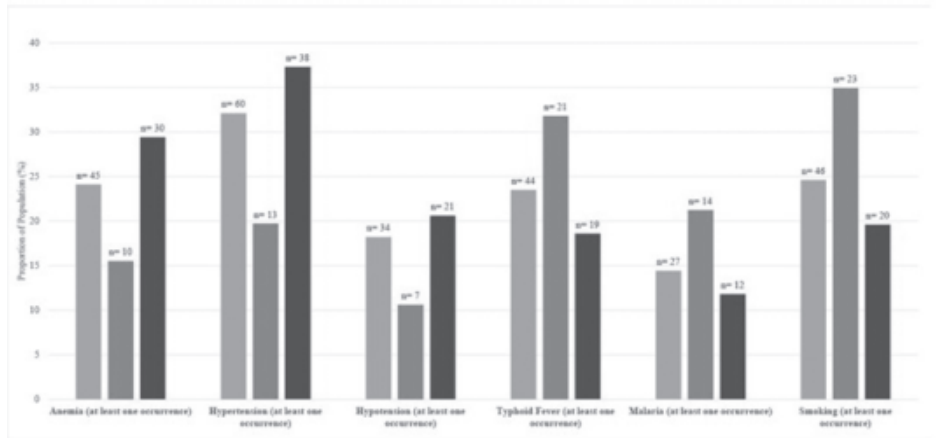


Figure 7. General health characteristics of households surveyed in Charnia area, Haryana - 2012.

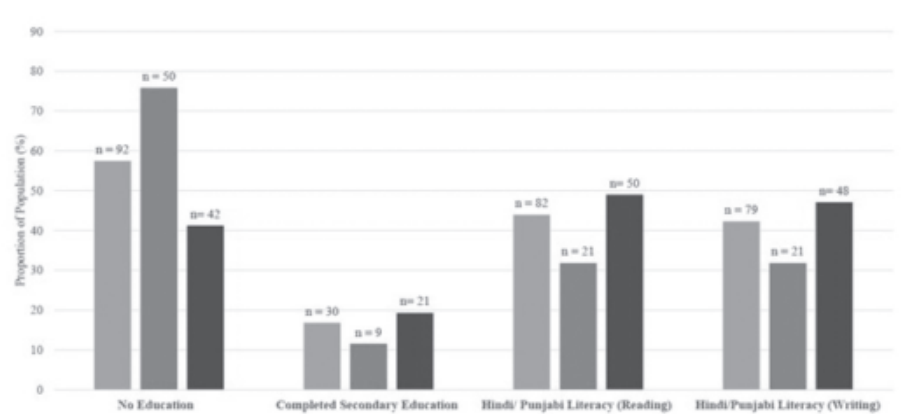


Figure 8. Reproductive health characteristics of households surveyed in Charnia area, Haryana - 2012.

in the children ( $p=0.045$ ). Put simply, the population type did not have a significant effect on the frequency for diarrhea in children, but children whose parents had lower education levels demonstrated a higher frequency of diarrhea.

### **Reproductive Health**

Females from the two groups demonstrated different prenatal care and delivery practices. Female BL (18%) were less likely to take iron supplementation during their pregnancies than NBL (33%) ( $p=0.02$ ). Female BL (52%) were also more likely to deliver at home with a traditional birth attendant (33%) ( $p=0.005$ ), while female NBL (36%) were found to be more likely to deliver in a hospital (18%) ( $p=0.004$ ) (Table 4; Figure 8).

Menstruation cycle regularity differed between the respondent groups as well; 33% of female BL reported regular menstrual cycles versus 44% of female NBL ( $p=0.01$ ). Cloth usage was regressed on respondent type while controlling for age and years of education; a 20% decrease was evident with every year increase in education (OR and 95% CI: 0.80, 0.70-0.92,  $p=0.001$ ).

Contraception use varied by group. Sixty percent of male BL were aware of condoms compared to 78% of male NBL. Twenty percent of male BL who were aware of condoms had used them versus 21% of male NBL ( $p=0.99$ ). Of the female BL, 77% were aware of copper-T IUD and 7% of the total female BL population had used it. Of the female NBL, 86% knew of this contraceptive and 22% of all female NBL had used it ( $p=0.04$ ).

### **Discussion**

This household-level needs assessment offers a cross-sectional perspective regarding the demographics and health of two different groups within the same geographic location. Despite geographic proximity, the data indicate disparities in education, health and socioeconomic status corresponding to various classes of employment. The study strongly suggests that long-term and consistent access to education and healthcare play a role in the disparities that exist between BL and NBL.

Individuals were surveyed from multiple brick zones and residential villages within the Charnia area; the three adjacent villages had similar population compositions as the Charnia village. Accordingly, the needs assessment provided a representative cross-sectional perspective of the Charnia area's population subgroups of BL and NBL.

The study was limited by several factors. The absence of pre-existing literature meant that there was no data to which the results of this study can be compared. In addition, the survey had to be revised several times during fieldwork to remove inapplicable questions and reword questions for better phrasing. Some questions had variable response rates, particularly when the male or female head of the household was not present to answer gender-specific reproductive health questions. Future studies may attempt to decrease respondent recall bias (systemic error due to differences in how survey respondents remember information) by reorganizing questions and including fewer questions in the survey. Finally, because the study was not conducted during the brick-manufacturing season, the population sample size was limited by the relatively small BL population. The majority of the BL population comes from the surrounding states of Uttar Pradesh and Bihar. The BL population is highly migratory; individuals travel to the brick factories during the start of the brick-manufacturing season and leave during the monsoon season. The same BL may or may not return to Charnia during the next season. The high BL population turnover could affect the results, as

the health indicators measured could vary from year to year as the population changes.

Data from Charnia are consistent with existing studies describing poor socioeconomic status in populations with lower education.<sup>11,12</sup> The results of this study indicate that BL are in general less educated than NBL; both BL children and adults had fewer years of attendance of formal schooling than NBL children, contributing to lower literacy rates. In addition, BL have fewer material possessions, indicating a difference in wealth.

Charnia's BL demonstrated a need for health education. Many of the BLs are from Uttar Pradesh and Bihar, which have the highest rates of health and education disparities in India.<sup>13</sup> As the BL population is mostly migratory, BL are also unable to fully utilize the health and education infrastructure in either their home or work states. Rates of chronic disease and infectious disease were similar between BL and NBL, but BL reported more symptoms of illness. Thus, BL may not be as knowledgeable about which diseases arise from those symptoms. Targeted health education programs designed to be completed before the end of the brick-manufacturing season could help BL understand the consequences of various symptoms, prevent chronic and infectious disease and improve the accuracy of self-reported data.

Community-based health education, with a focus on available prenatal resources, may also encourage and increase utilization of existing resources.<sup>13</sup> Although governmental programs exist to subsidize hospital deliveries and provide prenatal care by distributing iron and folic-acid supplements, few BL participate. This may be due to distrust in the public health system as well as their migratory lifestyle.<sup>14</sup> These governmental programs rely on following up with patients in person and on a regular basis; however, there is currently no centralized record of each follow-up visit. With the migrant BL population, continuous follow-up is difficult as the population moves. This issue can be alleviated through mobile health technologies and electronic medical record systems, which would allow government health workers to track patients and their health history as they change locations. In order to design an effective educational curriculum, follow-up studies should be designed to assess specific illnesses or conditions. For instance, a detailed survey on maternal/child health and nutritional behavior should include objective biomarkers like hemoglobin measurements, blood pressure and anthropometrics.

Studies have indicated the potential benefits of community health worker (CHW) programs, which can target educational and health disparities.<sup>15,16</sup> CHW programs work by recruiting, training and educating community members to advocate for behavior change in their own communities. These studies have shown that CHW programs can increase the effectiveness of health interventions, especially those that target behavior change. For example, in Charnia, community members could advocate for preventive care and increase awareness, especially for programs targeting prenatal care in both the BL and NBL. Community-level interventions, such as increasing the rate of BL children attending school, may also help reduce other lifestyle disparities between BL and NBL.

Moreover, mobile health technology can enable health workers to assess and track prevalent conditions such as cardiovascular disease, malnutrition and anemia.<sup>17,18,19</sup> Mobile health technology has already been implemented in government health worker systems in India to help track patient health information and help improve communication between health workers in the field and government primary health centers. In this way, mobile technology can be used to connect government health



facilities and underserved rural areas. In Charnia, there was no difference in the possession of mobile phones between BL and NBL despite differences in income. Research on technology usage has shown that mobile phones are ubiquitous throughout India regardless of socioeconomic status.<sup>20</sup> Although further research must be conducted to analyze the reasons for this trend in Charnia, it may be hypothesized that BL utilize mobile phones to remain in contact with their family members in other parts of India. As such, interventions that specifically utilize mobile phones could be successful in reducing the health disparities in Charnia. For example, SMS reminders for medication adherence could be implemented. Follow-up research should further explore the feasibility of mobile health technology and CHW programs in Charnia.

### Conclusion

Notable disparities can exist in the same geographical location, as demonstrated by the differences between Charnia's BL and NBL. Overall, BL had fewer material possessions, lower rates of education and lower rates of literacy compared to NBL. BL were also more likely to have a home birth delivery and less likely to have access to IFA supplementation during their pregnancies. Disparities such as these are linked to socioeconomic, health and educational differences, which can largely be associated with the BL population's migratory nature. BL's migratory lifestyle may pose challenges in obtaining medical care provided by the government, accessing continual health education, enrolling in schools and maintaining a stable income. These disparities must be targeted through a sustainable community-based approach that recognizes and addresses the varying population dynamics of BL and NBL in Charnia. Interventions targeting migrant populations specifically must be designed and implemented differently than interventions targeting more stable, permanent populations.

### Acknowledgments

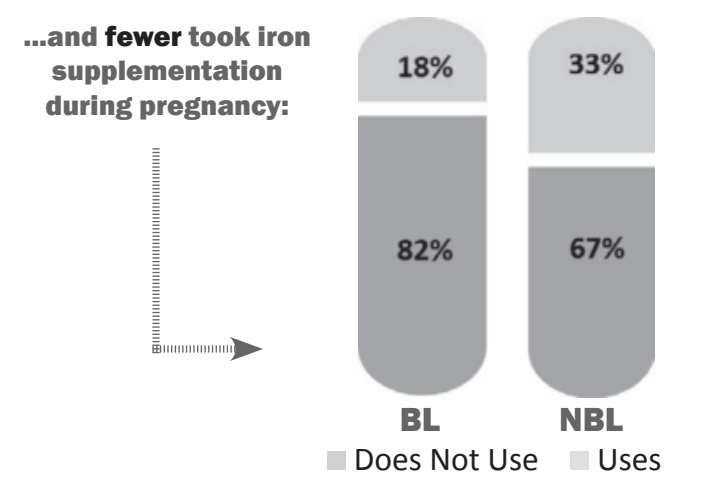
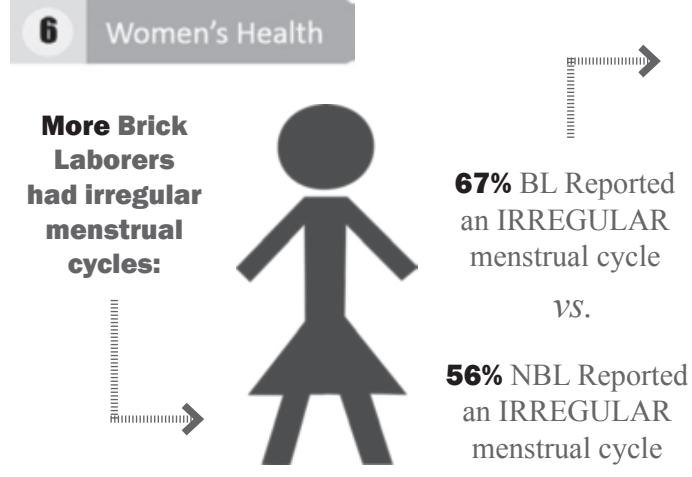
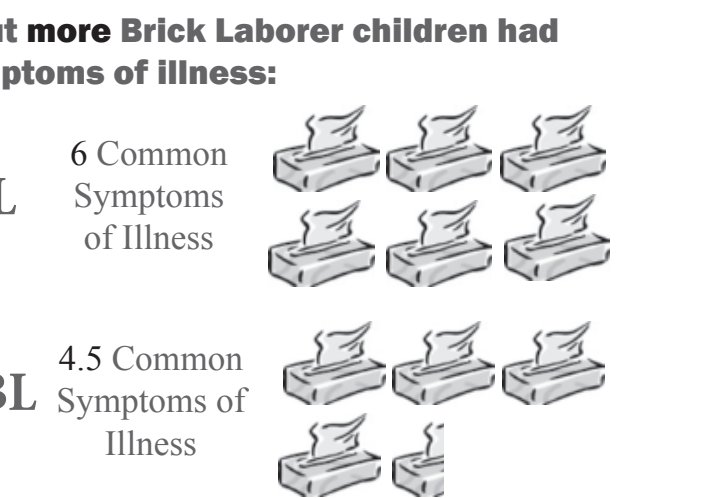
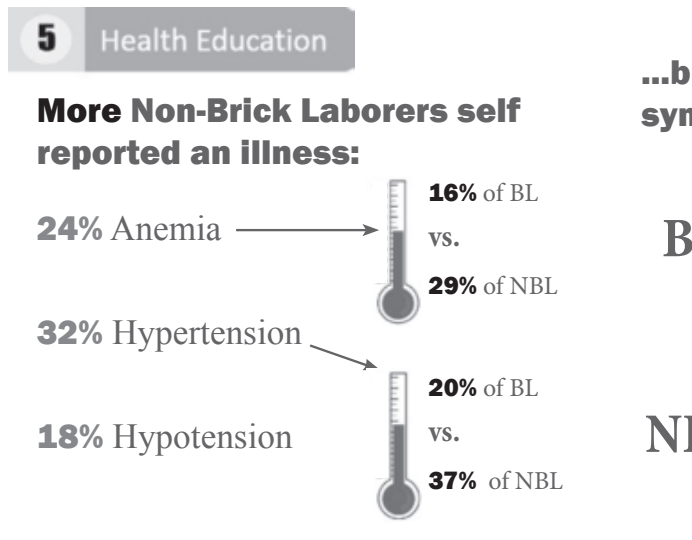
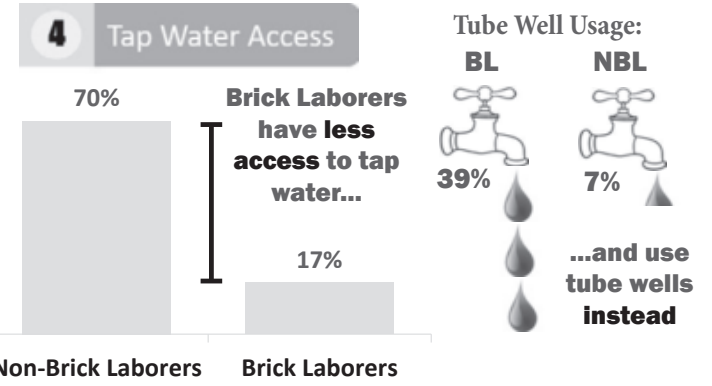
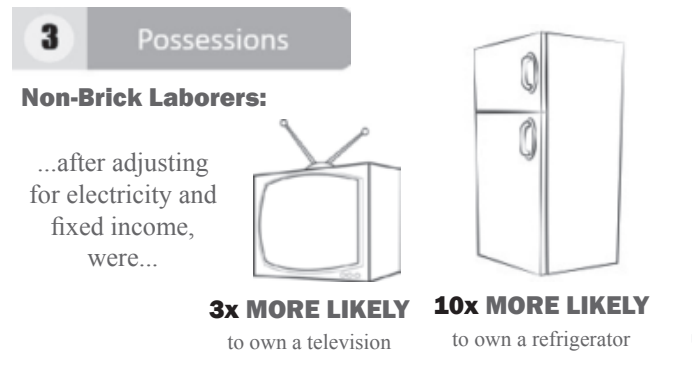
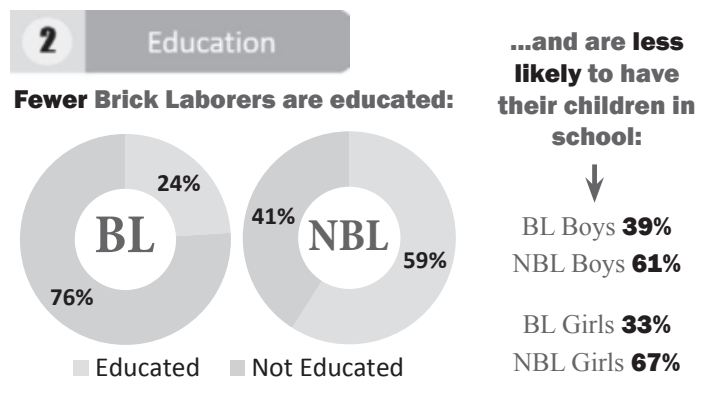
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## Substance Use and Condom Use Among the HIV Population at Clínica de Familia La Romana, Dominican Republic

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**The primary purpose of this cross-sectional investigation was to quantify illicit substance use among the HIV positive population at Clínica de Familia La Romana in the Dominican Republic. The secondary goal was to identify whether there exists a relationship between alcohol consumption and condom use. Of the 97 participants who were interviewed in the study, 49% self-reported alcohol or tobacco use in the last three months. Based on the calculated ASSIST risk score, 20% of participants were classified as “moderate” or “high risk,” requiring an intervention. Additionally, 51% of the sample reported having sexual intercourse in the last 30 days. Out of the 49 participants who were sexually active, 67% reported using a condom during their last sexual experience, 31% reported not using a condom and the remaining 2% declined to respond. Contrary to prior research, no association was found between alcohol consumption and unprotected sex at Clínica de Familia La Romana, possibly due to the low percentage of patients that report consuming alcohol frequently.**

### Introduction

The Caribbean has the second highest prevalence of human immunodeficiency virus (HIV) globally, after sub-Saharan Africa, with an adult prevalence of 1%.<sup>1</sup> Within the Caribbean, the Dominican Republic (DR) reports the second highest prevalence of HIV infection, following Haiti, estimated at 0.7% for those 15 to 49 years old.<sup>1,2</sup> Still, the estimated number of new infections has decreased over the past years from 41,000 in 2003 to less than 1,000 in 2013.<sup>3</sup> A major reason for this decline was the introduction of highly active antiretroviral treatment (HAART) in 2004.<sup>4</sup>

The primary mode of HIV transmission in the Dominican Republic is via heterosexual sexual intercourse.<sup>5</sup> HIV transmission is most prevalent within certain regions of the DR, particularly those with high tourism, such as La Romana, Puerto Plata and Santo Domingo.<sup>6</sup> A review of epidemiological studies suggests that HIV is prevalent in tourist areas due to the mixing of local population with outside carriers, commercial sex work heavy alcohol and illicit drug use.<sup>7</sup>

The primary narcotics used in the Caribbean are alcohol, marijuana and cocaine; the injection of drugs, such as heroin, remains rare.<sup>7</sup> In contrast to the rest of the Caribbean, research has found drug abuse in the DR to be low, with the exception of alcohol.<sup>6,8</sup> This finding is of particular importance for people living with HIV/AIDS (PLWHA) due to the impact of alcohol on HAART treatment and adherence. An overwhelming amount of research has found that alcohol consumption has deleterious effects on markers of immunological functioning and viral suppression.<sup>9-11</sup> Other research has found a significant association be-

tween alcohol and drug use and non-adherence to HAART therapy.<sup>12,13</sup>

In a study by Harris et al. (2011), researchers investigated barriers to medical adherence in 300 HIV-infected individuals in the Dominican Republic. Researchers found that alcohol users were 2.5 times more likely (95% CI: 1.4-4.5) to be non-adherent to medical treatment compared to non-users.<sup>13</sup> The benefits of high adherence rates are consistent across cultural settings and include increased immune response, lower rates of resistance and mortality and improved survival.<sup>13</sup> Therefore, there are several significant health concerns associated with alcohol consumption and drug use among patients with HIV.

Another health concern associated with alcohol consumption is unprotected sex, particularly among PLWHA. Approximately 70% PLWHA remain sexually active after diagnosis and one-third of PLWHA engage in unprotected sex.<sup>14,15</sup> Alcohol is a frequently implicated risk factor for unprotected sex, and alcohol consumption tends to be more prevalent among PLWHA than the general population.<sup>16,17</sup> In a 2010 meta-analysis, Baliunas et al. found that those who consumed alcohol prior to or during sexual relations were at an 87% higher risk of acquiring HIV.<sup>18</sup> In a literature review and meta-analysis of 27 relevant studies, Shuper et al. (2009) demonstrated that alcohol consumption in sexual contexts was significantly associated with unprotected sex among PLWHA.<sup>19</sup>

Most of the research on alcohol consumption and unprotected sex in the DR has revolved around sex worker populations because sex work is legal, and sex workers represent an especially vulnerable population. Research has found that drugs are used prior to sexual relations in



order to earn more money, even at the cost of having unprotected sex.<sup>20</sup> Research on alcohol consumption and risky sex among PLWHA who are not sex workers in the DR remains rare.

Substance use has not previously been quantified among HIV patients at Clínica de Familia La Romana (CFLR). Additionally, the association between alcohol consumption and unprotected sex has not been previously investigated. This study assessed both factors through interviews in order to achieve an understanding of alcohol and substance use within this population and to determine if certain subpopulations within the clinic are at higher risk for transmitting the virus.

## Methods

PubMed and Google Scholar databases were queried for articles that had standardized questionnaires on substance use that were culturally relevant to the clinic's population. After extensive research, a substance abuse program protocol was obtained from the World Health Organization website. The manual explains how to implement the Alcohol, Smoking and Substance Involvement Screening Test ("ASSIST"), an eight-item questionnaire developed by an international group of addiction researchers and clinicians.<sup>21</sup> The ASSIST questionnaire determines a risk score for each substance by assigning greater involvement, i.e. drinking daily versus monthly, with a higher risk score (see supplemental information for ASSIST questionnaire and scoring). Based on the risk score for each substance, participants are placed in either "low," "moderate" or "high risk" categories and assigned the appropriate intervention for that level of use (i.e., "no treatment," "brief intervention" or "referral to a specialist," respectively).

The ASSIST questionnaire is paired with a "Brief Intervention" (also from WHO), which contains detailed instructions on how health care workers can conduct an intervention for patients at

"moderate" to "high risk" for substance use.<sup>21</sup> The brief intervention consists of: a feedback report card that lists health risks associated with chronic use for each substance; a self-help handout that provides participants with strategies to reduce substance use; and a motivational interviewing dialogue that enables the patient and health care worker to discuss triggers and build a support system for the patient. The World Health Organization translated the ASSIST manual and brief intervention to Spanish and has implemented both in cultural settings similar to those in the DR. The manual and intervention have proven to be effective at significantly reducing the ASSIST scores of patients compared to patients not receiving the intervention. Moreover, 80% of participants reported a desire to cut down on their substance use after receiving the brief intervention.<sup>21</sup>

The eight-item questionnaire was combined with a standard demographic information questionnaire and a sexual history questionnaire adapted from another study at the clinic. This three-part questionnaire was performed on a convenience sample of 100 patients in the HIV program at CFLR. The HIV program includes all patients with HIV except for sex workers, who are part of the women's program at the clinic. Only adults (18+) who could communicate in Spanish were entered into the study. Adult patients who were waiting for their doctors' appointments at CFLR were randomly sampled by asking every third participant whether they would like to participate in a brief questionnaire.

Patients who accepted were taken into a private consultation office where they were told that the study consisted of questions on: their demographic information; consumption of alcohol, tobacco, illicit drugs and prescription medications that may have been taken more frequently or in higher doses than prescribed; and their sexual history in terms of condom use. Participants were told that their responses would remain strictly confidential and would not affect their treatment at the clinic.

**Table 1: Demographic Information**

| Category                  |                          | Count | Percent |
|---------------------------|--------------------------|-------|---------|
| <b>Sex</b>                | Female                   | 50    | 52%     |
|                           | Male                     | 47    | 48%     |
| <b>Age</b>                | 18-25                    | 6     | 6%      |
|                           | 26-45                    | 55    | 57%     |
|                           | 46-78                    | 36    | 37%     |
| <b>Nationality</b>        | Dominican                | 82    | 85%     |
|                           | Haitian                  | 15    | 15%     |
| <b>Education</b>          | Primary                  | 38    | 39%     |
|                           | Secondary                | 38    | 39%     |
|                           | University               | 7     | 7%      |
|                           | None                     | 14    | 14%     |
| <b>Employment</b>         | Unemployed               | 47    | 48%     |
|                           | Salary                   | 29    | 30%     |
|                           | Private Business         | 21    | 22%     |
| <b>Civil Status</b>       | Single                   | 40    | 41%     |
|                           | Married                  | 13    | 13%     |
|                           | Divorced                 | 7     | 7%      |
|                           | Liberal Union            | 25    | 26%     |
|                           | Stable Relationship      | 5     | 5%      |
|                           | Second or Third Marriage | 1     | 1%      |
|                           | Widow                    | 6     | 6%      |
| <b>Living Status</b>      | Alone                    | 19    | 20%     |
|                           | With Someone             | 78    | 80%     |
| <b>Sexual Orientation</b> | Heterosexual             | 85    | 88%     |
|                           | Homosexual               | 5     | 5%      |
|                           | Asexual                  | 6     | 6%      |
|                           | Bisexual                 | 1     | 1%      |
| <b>Religion</b>           | Catholic                 | 30    | 31%     |
|                           | Evangelical Christian    | 34    | 35%     |
|                           | Pentecostal              | 10    | 10%     |
|                           | Adventist                | 3     | 3%      |
|                           | None                     | 18    | 19%     |
|                           | Other                    | 2     | 2%      |

Additionally, they were informed that they could refuse to respond to any question and/or terminate their participation in the study at any point. Finally, participants were asked to give verbal consent if they agreed to enter the study.

A health care worker completed all questionnaires through a guided interview in Spanish to ensure that participants clearly understood the questions and could respond to the best of their ability. From the ASSIST questionnaire, the health care worker calculated the participant's risk score for each substance and offered a brief intervention for patients at "moderate" to "high risk" for substance use. If the participant accepted, s/he was given the feedback report card with her/his risk score and a list of health concerns associated with chronic use for each substance. For example, some of the listed health risks related to chronic alcohol consumption are memory loss, liver and pancreatic disease and compromised immune response. The risk score was used to start a discussion with the participant about her/his drug use.

The motivational interviewing phase of the intervention began by asking participants if they had experienced any of the health concerns listed in the feedback report card. The participant was then asked to

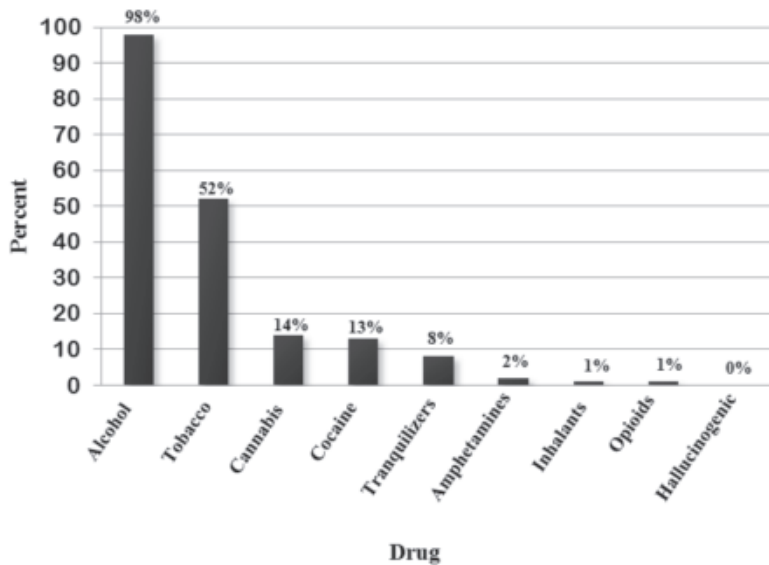


Figure 1. Substance Use At Least Once in Lifetime (Data from responses to Question 1 of the ASSIST questionnaire).

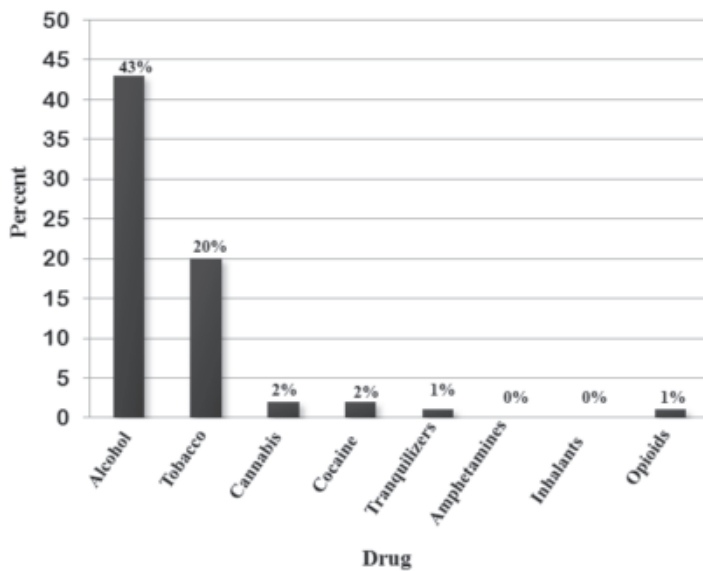


Figure 2. Substance Use in the Last Three Months (Data from responses to Question 2 of the ASSIST questionnaire).

reflect on the positive and negative effects of her/his substance use, if the negative effects outweighed the positive and if that reflection was enough to motivate them to quit. Then, the participant and health care worker constructed a support network that included family, friends and the clinic's psychologist. Those who wanted to reduce and eliminate their substance use were referred to the clinic's psychologist for continued motivational therapy. Participants who were hesitant to quit were reminded of the associated health risks and informed that the psychologist would always be a resource should they change their minds. For participants at high risk, the health care worker concluded the motivational interviewing phase by introducing participants to the clinic's psychologist to encourage follow-up treatment.

Results

Of the 100 patients interviewed, 97 completed the full questionnaire. Table 1 displays the results of the demographic information collected. In general, the study consisted of an approximately equal ratio of men to women (48% to 52%, respectively) and a mean age of 43

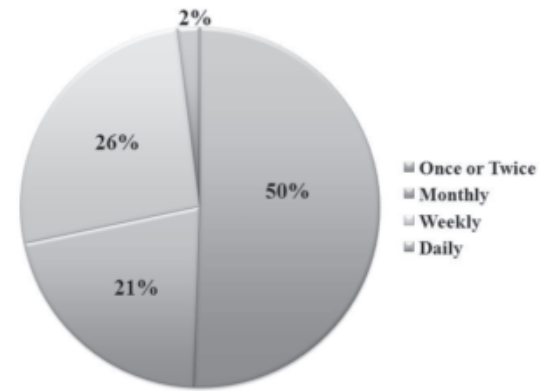


Figure 3. Frequency of Tobacco Use in the Last Three Months (Data from responses to Question 2 of the ASSIST questionnaire).

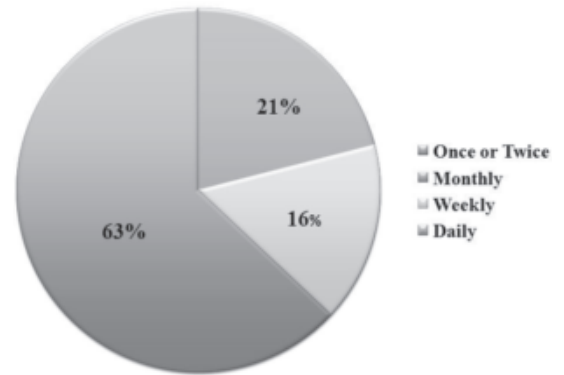


Figure 4. Frequency of Alcohol Use in the Last Three Months (Data from responses to Question 2 of the ASSIST questionnaire).

years. The sample consisted primarily of Dominican patients (85%) with 15% identifying as Haitian. Participants reported completion of either primary (39%) or secondary (39%) schooling and a substantial number were unemployed (48%). They identified predominantly as heterosexual (88%) and single (41%) but did not reside alone (80%). The majority of patients (81%) identified as religious, with 79% reporting Christianity as their religion.

The second part of the questionnaire quantified the amount of substance use in the sample. 99% of the study participants had used alcohol or tobacco at least once in the last 12 months. Figure 1 displays the amount of substance use for each drug used in the past 12 months. The most common drug used was alcohol (98%), followed by tobacco (52%). The other substances were used at lower rates and only in conjunction with alcohol or tobacco.

When asked about substance use in the last three months, 48 (49%) of the study participants reported using substances from once or twice to daily. Figure 2 displays the amount of substance use in the last three months. Again, alcohol was the most commonly used drug: 42 participants (43%) reported consuming alcohol in the last three months, while only 19 (20%) reported using tobacco; 4 participants (4%) reported using the remaining substances and consumed them rarely.

Figure 3 and 4 further examine the two most used substances, depicting the frequency of use in the last three months. Tobacco was used more frequently with 12 out of 19 participants (63%) reporting use on a daily basis, while alcohol was used less frequently with 30 out of 42 participants (71%) reporting use once or twice to monthly.

Of the 97 participants that completed the questionnaires, 19 (20%) qualified for an intervention. All but one patient agreed to the

intervention. Of the 19 that required an intervention, 12 (63%) required it for one substance, 5 (26%) required it for two substances and 2 (11%) required it for three substances. Despite having a greater number of alcohol users, only 6 out of the 42 participants (14%) that reported consuming alcohol in the last 3 months required an intervention for alcohol, whereas 18 out of 19 participants (95%) that reported tobacco use required an intervention for tobacco. 5 out of 6 participants that required an intervention for alcohol were also smokers. All participants that required an intervention for a drug other than alcohol or tobacco also required an intervention for alcohol and/or tobacco.

The third part of the questionnaire asked about sexual behavior and condom use. Of the 97 participants, 49 (51%) reported being sexually active (as defined by having sex in the last 30 days). Of those 49 participants, 33 (67%) reported using a condom during their last sexual encounter, whereas 15 (31%) reported not using a condom. The remaining participant (the last 2%) chose not to respond.

Alcohol use prior to or during sexual encounter was quantified. Of the 49 participants who were currently sexually active, 12 (24%) reported not consuming alcohol prior to or during their last sexual encounter, while the other 12 (24%) reported that they had. The remaining 25 participants (51%) had not consumed alcohol in the last 3 months. Of the 12 patients who had consumed alcohol in conjunction with sexual intercourse, 7 (58%) reported using a condom, whereas 4 (33%) had not used a condom; the final participant chose not to respond. As shown in Figure 5, the relative risk<sup>22</sup> of unprotected sex for those who consumed alcohol was 1.45 times (95% CI 0.41-5.05) that of those who did not.

## Discussion

The present cross-sectional investigation consisted of a three-part questionnaire that was implemented as an interview to quantify alcohol, tobacco and illicit substance use among patients in the HIV program at Clínica de Familia La Romana (CFLR). The results can be used to estimate the overall number of patients at CFLR who consume drugs and the frequency of their use. The findings suggest that alcohol and other substances are consumed at lower rates at CFLR compared to PLWHA populations in the Caribbean, the United States, and other regions of the DR.<sup>5,17,20,23</sup>

There are several limitations in the design of the study that should be addressed. First, there is a reporting bias that is associated with questionnaire-type settings. The ways in which alcohol and other substances interact with the immune system and ART treatment had been explained to the patients at the clinic, and they were aware that they should not consume drugs while on anti-retroviral therapy. Therefore, when a healthcare worker asked about substance use, participants were likely to underreport use. Another potential outcome of a more knowledgeable population is a "healthier" population in which patients consume fewer drugs because they know that it negatively impacts their health. This might explain why there was a lower prevalence of reported alcohol and substance use at CFLR.

A second variable that may have influenced the amount of drug use is demographic factors. There was no association found at the 5% level of significance between substance use and several demographic factors, namely age, sex, education and religion. About half (49%) of the par-

ticipants reported having reduced their drug use after HIV diagnosis. Several participants attributed their low substance use to their religious beliefs. Although the information was not experimentally collected, the predominant explanation for this reduction in use was that patients joined a Christian church after diagnosis. Given that participants explained that their religious beliefs led them to lower or eliminate their use of alcohol and other substances, the potential function of religion as a protective factor merits further investigation. Results from the second part of the study found that approximately half (51%) of the population remained sexually active after diagnosis, a lower rate compared to previous literature reviews, such as Crepaz and Marks (2002), who found that 70% remain sexually active. Despite a lower rate of sexual activity, a third of the sample (31%) was engaging in unprotected sex, a finding that is consistent with other research findings.<sup>15</sup> Once again, these results could have been affected by a reporting bias that would result in under-reporting sexual activity and over-reporting condom use.

The selection of the sample is another limiting factor that could have impacted the study's results. Participants were selected on a convenience basis: patients who were waiting for their doctors' appointments were asked if they would like to participate in the study. Only those who agreed to be interviewed entered into the study, giving rise to a

self-selection bias: patients who were more open to talk about their substance use and sexual history enrolled in the study, while those who were not, were excluded from the sample. This form of enrollment resulted in a relatively small sample size of 97 participants. A small sample size can give rise to doubt that the sample is reflective of the entire population. Therefore, the small sample is a significant weakness in the study that limits the validity of the data collected.

## Research has found that drugs are used prior to sexual exploits in order to earn more money, even at the cost of having unprotected sex.

Contrary to prior research, there was no association between alcohol consumption and unprotected sex. The relative risk ratio found that unprotected sex was 1.45 times more likely when having consumed alcohol prior to or during sex. However, the confidence interval was broad (0.41 to 5.05), indicating that the finding was not significant, possibly because of the small sample size. Still, even with a larger sample unprotected sex and alcohol consumption may not be related in this population because of the small number of patients who reported drinking alcohol on a frequent basis.

Despite these limitations, the findings of this primary investigation of substance use at CFLR are important to gain a general idea of substance use among patients in similar populations worldwide. Additionally, the findings can be used to direct further investigations that might provide more concrete findings on substance use at CFLR and in other populations

## Conclusion

The results from the study found that two major concerns persist within the targeted population: alcohol and other substance use and low condom use. Despite the relatively low frequency of alcohol and other substance use at CFLR, about half of the surveyed sample reported consuming alcohol in the last three months which can further compromise their immune system and potentially contribute to non-adherence. The importance of treatment adherence is clear in medical literature, yet it



| Relative Risk                              |     | Used Condom |     | Total |
|--|-----|-------------|-----|-------|
|  |     | No          | Yes |       |
| Drank Alcohol<br>Prior to or<br>During Sex | Yes | 4           | 7   | 11    |
|  | No  | 3           | 9   | 12    |
|  |     | 7           | 16  | 23    |

Relative Risk =  $\frac{\text{probability of event when exposed}}{\text{probability of event when not exposed}}$

$$RR = \frac{4/11}{3/12} = \frac{16}{11} = 1.45$$

$$\text{Confidence Interval} = \ln(1.45) \pm 1.96 \sqrt{\frac{(7/4)}{11} + \frac{(9/3)}{12}}$$

$$\text{Confidence Interval} = (0.41, 5.05)$$

**Figure 3.** Relative Risk of Consuming Alcohol Prior to or During Sex and Condom Use.

remains unknown whether alcohol and drugs directly impact patient adherence at CFLR. A follow-up study could investigate whether patients who received the intervention obtain a lower risk score on the ASSIST questionnaire compared to before the intervention and cross-analyze that data with biomarkers for adherence, such as viral load.

As stated earlier, the small sample size limits the validity of the data collected and whether it reflects the HIV population at CFLR as a whole. Despite this drawback, the study presents findings that deserve further investigation, namely the low frequency of alcohol consumption and lack of association between alcohol consumption and unprotected sex. Therefore, a repeated investigation that recruits a larger sample might lend more support to this finding and provide a concrete conclusion about whether alcohol consumption presupposes unprotected sex for the HIV population at CFLR.

Finally, it is concerning that a third of the population is engaging in unprotected sex despite their knowledge of HIV transmission. This study did not set out to investigate the factors that contribute to low condom use, so it would be of use to survey the population at CFLR and find out the reasons for low condom use.

In conclusion, the present investigation provided a preliminary investigation into substance use at Clínica de Familia La Romana. A substance abuse program was designed to ensure that doctors are aware of substance use among their patients, which will enable doctors and patients to better holistically understand demographic aspects that contribute

to patient health. In addition, a brief intervention program was incorporated into the clinic's setting so as to provide at-risk patients with the necessary resources to reduce and eliminate their substance use.

### Supplemental Information

ASSIST questionnaire (v3.1) from the World Health Organization that quantifies substance use and categorizes patients as "low," "moderate" or "high risk" depending on the

patient's risk score as evaluated below. (Questionnaire was reformatted to fit on the page, but no content was altered).

The point of this preliminary investigation was to learn about integrating the World Health Organization's (WHO) substance use questions in the clinic's intake form in order to conduct a needs assessment, and to eventually design and adapt the WHO intervention program based on the results. This internal project required research to structure the inclusion of the substance use questions and to adapt them according to patients' needs. The goal is to replicate this study, expanding it based on our findings and submitting the study protocol to the appropriate ethics review committees, to conduct a needs assessment across a larger sample. Additionally, based on these initial findings it would be informative to investigate more in depth the factors that contribute to low condom use.

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**The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST v3.1)**

Clinician name: \_\_\_\_\_ Clinic: \_\_\_\_\_ Client ID or Name: \_\_\_\_\_ Date: \_\_\_\_\_

**Introduction** (please read to client or adapt for local circumstances)

The following questions ask about your experience of using alcohol, tobacco products and other drugs across your lifetime and in the past three months. These substances can be smoked, swallowed, snorted, inhaled or injected (show response card). Some of the substances listed may be prescribed by a doctor (like amphetamines, sedatives, pain medications). For this interview, we will **not** record medications that are used **as prescribed** by your doctor. However, if you have taken such medications for reasons **other** than prescription, or taken them more frequently or at higher doses than prescribed, please let me know. While we are also interested in knowing about your use of various illicit drugs, please be assured that information on such use will be treated as strictly confidential. Before asking questions, give ASSIST response card to client.

| Question 1: In your life, which of the following substances have you ever used (non-medical use only)?          |   |     |
|---|---|-----|
| a. Tobacco products (cigarettes, chewing tobacco, cigars, etc.)   | No  | Yes |
| b. Alcoholic beverages (beer, wine, spirits, etc.)  | No  | Yes |
| c. Cannabis (marijuana, pot, grass, hash, etc.)   | No  | Yes |
| d. Cocaine (coke, crack, etc.)  | No  | Yes |
| e. Amphetamine-type stimulants (speed, meth, ecstasy, etc.)   | No  | Yes |
| f. Inhalants (nitrous, glue, petrol, paint thinner, etc.)   | No  | Yes |
| g. Sedatives or sleeping pills (diazepam, alprazolam, flunitrazepam, midazolam, etc.)                           | No  | Yes |
| h. Hallucinogens (LSD, acid, mushrooms, trips, ketamine, etc.)  | No  | Yes |
| i. Opioids (heroin, morphine, methadone, buprenorphine, codeine, etc.)  | No  | Yes |
| j. Other – specify: _____   | No  | Yes |
| Probe if all answers are negative: "Not even when you were in school?"<br>If "No" to all items, stop interview. | If "Yes" to any of these items, ask Q2 for each substance ever used |     |

| Question 2: In the past three months, how often have you used the substances you mentioned (first drug, second drug, etc.)?   | Never | Once or twice | Monthly | Weekly | Daily or almost daily |
|---|-------|---------------|---------|--------|-----------------------|
| a. Tobacco products (cigarettes, chewing tobacco, cigars, etc.)   | 0     | 2             | 3       | 4      | 6                     |
| b. Alcoholic beverages (beer, wine, spirits, etc.)  | 0     | 2             | 3       | 4      | 6                     |
| c. Cannabis (marijuana, pot, grass, hash, etc.)   | 0     | 2             | 3       | 4      | 6                     |
| d. Cocaine (coke, crack, etc.)  | 0     | 2             | 3       | 4      | 6                     |
| e. Amphetamine-type stimulants (speed, meth, ecstasy, etc.)   | 0     | 2             | 3       | 4      | 6                     |
| f. Inhalants (nitrous, glue, petrol, paint thinner, etc.)   | 0     | 2             | 3       | 4      | 6                     |
| g. Sedatives or sleeping pills (diazepam, alprazolam, flunitrazepam, midazolam, etc.)   | 0     | 2             | 3       | 4      | 6                     |
| h. Hallucinogens (LSD, acid, mushrooms, trips, ketamine, etc.)  | 0     | 2             | 3       | 4      | 6                     |
| i. Opioids (heroin, morphine, methadone, buprenorphine, codeine, etc.)  | 0     | 2             | 3       | 4      | 6                     |
| j. Other – specify: _____   | 0     | 2             | 3       | 4      | 6                     |
| If "Never" to all items in Q2, skip to Q6.<br>If any substances in Q2 were used in the previous three months, continue with Questions 3, 4 & 5 for each substance used. |       |               |         |        |                       |

| Question 3: During the past three months, how often have you had a strong desire or urge to use (first drug, second drug, etc.)? | Never | Once or twice | Monthly | Weekly | Daily or almost daily |
|--|-------|---------------|---------|--------|-----------------------|
| a. Tobacco products (cigarettes, chewing tobacco, cigars, etc.)  | 0     | 3             | 4       | 5      | 6                     |
| b. Alcoholic beverages (beer, wine, spirits, etc.)   | 0     | 3             | 4       | 5      | 6                     |
| c. Cannabis (marijuana, pot, grass, hash, etc.)  | 0     | 3             | 4       | 5      | 6                     |
| d. Cocaine (coke, crack, etc.)   | 0     | 3             | 4       | 5      | 6                     |
| e. Amphetamine-type stimulants (speed, meth, ecstasy, etc.)  | 0     | 3             | 4       | 5      | 6                     |
| f. Inhalants (nitrous, glue, petrol, paint thinner, etc.)  | 0     | 3             | 4       | 5      | 6                     |
| g. Sedatives or sleeping pills (diazepam, alprazolam, flunitrazepam, midazolam, etc.)  | 0     | 3             | 4       | 5      | 6                     |
| h. Hallucinogens (LSD, acid, mushrooms, trips, ketamine, etc.)   | 0     | 3             | 4       | 5      | 6                     |
| i. Opioids (heroin, morphine, methadone, buprenorphine, codeine, etc.)   | 0     | 3             | 4       | 5      | 6                     |
| j. Other – specify: _____  | 0     | 3             | 4       | 5      | 6                     |

| Question 4: During the past three months, how often has your use of (first drug, second drug, etc.) led to health, social, legal or financial problems? | Never | Once or twice | Monthly | Weekly | Daily or almost daily |
|---|-------|---------------|---------|--------|-----------------------|
| a. Tobacco products (cigarettes, chewing tobacco, cigars, etc.)   | 0     | 4             | 5       | 6      | 7                     |
| b. Alcoholic beverages (beer, wine, spirits, etc.)  | 0     | 4             | 5       | 6      | 7                     |
| c. Cannabis (marijuana, pot, grass, hash, etc.)   | 0     | 4             | 5       | 6      | 7                     |
| d. Cocaine (coke, crack, etc.)  | 0     | 4             | 5       | 6      | 7                     |
| e. Amphetamine-type stimulants (speed, meth, ecstasy, etc.)   | 0     | 4             | 5       | 6      | 7                     |
| f. Inhalants (nitrous, glue, petrol, paint thinner, etc.)   | 0     | 4             | 5       | 6      | 7                     |
| g. Sedatives or sleeping pills (diazepam, alprazolam, flunitrazepam, midazolam, etc.)   | 0     | 4             | 5       | 6      | 7                     |
| h. Hallucinogens (LSD, acid, mushrooms, trips, ketamine, etc.)  | 0     | 4             | 5       | 6      | 7                     |
| i. Opioids (heroin, morphine, methadone, buprenorphine, codeine, etc.)  | 0     | 4             | 5       | 6      | 7                     |
| j. Other – specify: _____   | 0     | 4             | 5       | 6      | 7                     |

## An Analysis of Health Care Systems in Two Countries Through Determining Public Satisfaction

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According to the World Health Organization's twenty-first century health care system rankings, Costa Rica ranked 36th in terms of health system performance, while the United States ranked 37th in the world.<sup>1</sup> The rankings are based on five composite indicators determined by public health experts: (1) overall level of population health, (2) health disparities and inequalities, (3) level of health system responsiveness, (4) distribution of responsiveness within the population and (5) distribution of financial burden within the population.<sup>1</sup> To understand what makes one health system better than another, it is pertinent to analyze them from different perspectives. Public health experts may be able to quantitatively determine if one system is better than another, but it is necessary to also incorporate viewpoints of the general population.<sup>2</sup> The purpose of this research is to investigate why the United States and Costa Rica are so closely ranked, even though their health systems are so different. To do so, interviews were conducted in both countries to determine public satisfaction with health care. Through statistical analysis, this study shows that there is a significant difference between the public satisfaction of participants in the United States and Costa Rica with the health care systems. Thus, in order to truly understand how effective a health care system is, it is beneficial to consider public opinion in addition to expert views. Future research may benefit from incorporating a larger-scale version of this study with the World Health Organization's findings, so as to combine public satisfaction and expert opinion and more effectively analyze health systems.

### Introduction

This study serves to supplement data from the World Health Organization (WHO) report, "Health Systems: Improving Performance" (2000).<sup>1</sup> It is intended as a pilot study to determine public satisfaction with the health care systems of the United States and Costa Rica, an additional factor that should be taken into account when establishing why these two extremely different countries with fundamentally opposite healthcare systems ranked one after the other in the WHO analysis. *Analysis of World Health Organization (WHO) rankings*

A health system is defined as comprising all the organizations, institutions, and resources that are devoted to producing health actions.<sup>1,3</sup> Health actions are any efforts—whether in personal health care, public health services or intersectoral initiatives—whose primary purpose is to improve the health of the population.<sup>1,3</sup> According to the World Health Organization, the success of a health system is measured using two metrics: goodness and fairness.<sup>1,2</sup> Goodness is the best attainable average level, and indicates that a health system is responding well to what people's expectations.<sup>1,2</sup> Fairness is the smallest feasible differences among individuals and groups, and is measured in how well a system responds to everyone, with the goal being equality without discrimination.<sup>1,2</sup> These are the basis of the WHO ranking system that was established in order to measure the performances of different health systems around the world.

The goal of the WHO report was to quantify what makes a health system good, what makes a health system fair and whether or not a health system performed as well as it could.<sup>1,2,4</sup> The actual WHO rank-

ings, done by public health experts, took into account the aforementioned five composite indicators in an attempt to index health care systems' success.<sup>1</sup> Each country was measured on levels of attainment and performance.<sup>1,2,4</sup> Attainment serves as a measure of what was actually achieved in reference to the three goals, while performance was the best result that could possibly be accomplished with the same resources, i.e. what the system would achieve in an ideal situation if it were not for poor structuring, misuse of power, inefficient organization and inadequate funding.<sup>1</sup>

This turn-of-the-century analysis was the first undertaking of a controversial, subjective topic.<sup>1</sup> WHO arrived at a conclusion and attained a "reasonably approximated" ranking of 191 countries' healthcare systems.<sup>1</sup>

### *The Two Health Systems: Characteristics and Current Problems*

The United States is unusual in that it is dominated by a private health care system. As of 2012, the US financed 48% of its health care publicly, meaning that 52% was private, or dependent on a source other than the government.<sup>5</sup> In contrast, Costa Rica has nearly 83% of its system financed by public providers, making it a predominantly public system.<sup>6</sup> The United States is the only industrialized country without nationalized health care.<sup>4</sup> And yet, the U.S. is at the forefront of innovation and research: it is responsible for over half of the world's major medications in the past two decades, accounts for 80% of major medical advances in the past 30 years and is the country with the highest survival rates for some of the most prevalent diseases worldwide including cancer and cardiac disease.<sup>4</sup> Meanwhile, as a government-run national



system and “one of the most effectively universalized health care systems in Latin America,” the majority of Costa Rican citizens are provided extensive health coverage affording them access to any and all medical services needed, an accomplishment that very few countries in the world have achieved.<sup>7</sup>

For the United States specifically, having a private system means that insurance is mainly employer-sponsored and administered by private companies. As of 2013, 53.9% of American citizens had this type of insurance.<sup>8</sup> In Costa Rica, the government is the main insurer and the provider of health care service. Two main governing bodies administer health services: Caja Costarricense de Seguro Social, or Costa Rican Social Security Administration (CCSS), and the Ministry of Health (MOH).<sup>7,9,10</sup> United States health care is financed individually, either through employers and employee premiums or by individual insurance premiums involving some out-of-pocket coverage.<sup>11</sup> On average in America, it costs \$4,479 per individual per year for insurance, or \$12,106 for a family.<sup>4,11</sup> Meanwhile, CCSS has multiple types of beneficiaries and health insurance is financed by tripartite contributions from employers, workers and the state.<sup>7,9</sup> This means that for a typical wage-earning individual, 22.91% of his or her salary goes to the social security system.<sup>7,9</sup>

Despite the predominantly private system in the United States, some public insurance is also available. Along the same vein, Costa Rica has some private aspects in addition to its public insurance. The public insurance aspect of the United States health care system is primarily focused around two main programs financed through federal and state taxes: Medicare and Medicaid.<sup>11</sup> Medicare is an entirely federal program that primarily covers people over the age of 65, whereas Medicaid is a state-administered program that is fairly comprehensive, but not universally accepted by all health practices and is only available to a select few, primarily low-income adults.<sup>11</sup> Meanwhile, to supplement the public aspect in certain areas, Costa Rica also has some private insurance available that is generally affordable and high-quality.<sup>7,10</sup> Some people purchase private insurance to avoid notoriously long waits for services such as elective procedures and other social security clinic delays.<sup>7,9</sup> As of 2008, about 25% of the Costa Rican population had private insurance in addition to social security.<sup>12</sup>

Both systems attempt to provide top-level service to the entire population, but are unable to do so primarily due to rising costs and lack of access to care. This is not unusual; these are the two main issues facing the majority of healthcare systems around the world.<sup>13</sup> The United States spends the most money on healthcare in the world, in terms of per capita and percentage of GDP.<sup>4</sup> And yet there is still a large burden of debt, increased taxation and uneven quality of care in that many Americans still do not receive the standard of care that they should.<sup>4,8</sup> The public aspect of the United States’ system is failing. Medicare and Medicaid have upwards of \$50 trillion in unfunded liabilities.<sup>4</sup> Americans may receive high quality care, but this care is extremely uneven in its distribution, where insurance is necessary to achieve the best medical treatments as otherwise costs are inconceivable.<sup>4,8</sup> The large number of uninsured Americans is therefore a major problem, one that must be

addressed in order for the health care system to perform at its best and achieve the overall goal of having a healthy population.

On the other hand, the Costa Rican system was designed for a working population, but due to recent population growth as a result of constant migration flow, many citizens live in poverty, which is detrimental to the efficiency of the system.<sup>7</sup> Additionally, the increased privatization of health services in Costa Rica threatens the quality of the system that currently exists.<sup>12</sup> It is a system based on primary assistance that, due to the increasing prevalence of chronic illnesses, is facing high demands of specialized treatment.<sup>12</sup> Thus, although the manifestation of these issues may be different in the two countries, in general the systems face very similar problems that significantly affect the overall quality of health care in these countries.<sup>4</sup>

#### *Why the WHO rankings are insufficient*

Interestingly the United States outranked Costa Rica in nearly every category in terms of composite indicators, as shown in Figure 1, and yet the two very different systems are overall placed 37th and 36th in the world.<sup>1,2</sup> Most significantly, the United States was first in level of health system responsiveness, while Costa Rica ranked 68<sup>th</sup>.<sup>1,2</sup> In terms of overall level of population health, the United States was 24th and Costa Rica was 40<sup>th</sup>.<sup>1</sup> Fairness in financial contribution was close, with the United States ranking 54-55th and Costa Rica 64-65<sup>th</sup>.<sup>1</sup> And for overall goal attainment, the United States was 15th and Costa Rica was 45<sup>th</sup>.<sup>1</sup> In contrast, in terms of overall performance on level of health, Costa Rica ranked 25th, while the United States was 72<sup>nd</sup>.<sup>1</sup>

Each of these factors contributed to the final rankings differently, and the full breakdown can be found in Annex Tables 5-10 of the World Health Report.<sup>1</sup> But most importantly, overall level of population health, health disparities and inequalities and distribution of financial burden within the population accounted for 25 percent each of the total goal achievement ranking.<sup>1</sup> And the remaining 25 percent was split between the final two indicators: level of health system responsiveness, and distribution of responsiveness within the population.<sup>1</sup> These factors all contributed to each systems’ attainment of goals, which was further evaluated to establish the overall performance. This measure of performance, the aforementioned best result that can possibly be accomplished based on the specific amount of resources available, was the primary endpoint of the analysis.<sup>1,2</sup> The overall ranking of the United States indicates that it has been unable to achieve what it should be able to with the resources that it has, most likely as a result of inefficient organization and rising costs.<sup>1,4</sup> According to the WHO’s metrics, the United States should be able to provide top-level and affordable care to a more significant percentage of the population.<sup>1,4</sup> Costa Rica is relatively successful in doing so, thus it has a higher level of performance.<sup>1,4</sup>

Although comprehensive rankings were achieved, the accuracy of such an analysis must be called into question. Despite its best efforts to remain impartial, the WHO study is based solely on the individual public health experts completing the study, whereas even the Director-General of the WHO specifically addresses the fact that “answers will depend on the perspective of the respondent” in the introduction to the World Health Report.<sup>1</sup> Therefore, the flaw lies in using only experts in the field to make these rankings and not incorporating multiple per-

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**Public satisfaction is important to health policy and government decision-making regarding health care, and is therefore paramount to the success of a complete analysis.**

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spectives. Public opinion in terms of satisfaction with health care should be taken into account. Even though public opinion can be difficult to quantify and often contains bias, it is still an important resource. Public satisfaction is important to health policy and government decision-making regarding health care and is therefore paramount to the success of a complete analysis.

Study Design

Setting and Sample Population

The process for determining public satisfaction with the Costa Rican and American health care systems involved surveying individuals in each country for their opinions on the system. Due to the logistics and time constraints of this pilot study, only one location in each country was utilized for sampling. Thus, in Costa Rica, the suburbs of San Jose were chosen, as San Jose is the capital of Costa Rica and a major metropolitan area, so both the city itself and surrounding area exhibit a diverse working-class population, many of whom do not have significant access to health care. The main subjects in the United States were also a

varied group of working-class individuals, specifically those visiting the emergency room at a non-profit hospital in Hampton, Virginia. A large percentage of the patient population in this city are not insured and do not have regular access to medical care, so they come to the emergency room for primary care needs. As a result, this area was the most equivalent to the region explored in Costa Rica, because both were intended to provide for the general population.

Measures of Public Satisfaction

Throughout the two weeks in each country, two different types of surveys were conducted in order to measure public satisfaction. For the first (short) survey that simply asked participants how satisfied they were with their health system, 25 individuals participated in each country. They were randomly selected from the subject population, with the intent of creating a study population with a variety of ages, genders and backgrounds – as heterogeneous as possible for the specific sample size. And for the second (long) survey, three individuals were chosen in each country. Selection of participants was similar to the short survey, but also depended on the participants' willingness to discuss more extensive personal information, so only three were sampled in each country. The second survey served as an interview and was intended to gain a more general and all-encompassing viewpoint to supplement information from the short surveys.

Prior to surveying, each individual was asked to sign a consent form, provided in both English and Spanish so that there were no issues with language barriers. The first type of survey was solely a quantitative measurement, asking people to rate the health care system on a scale of one through ten, one being extremely dissatisfied and ten being very satisfied with the system. The survey asked participants to rate the overall system, taking into account both their personal experiences and their thoughts of the system in general based on prior knowledge obtained through resources such as education or the experiences of other individuals. Other details that were

gathered about each person in order to get a better representation of the population included age, gender and their amount of exposure to health care in terms of the frequency with which the individual sought medical attention of any sort in a typical year.

The second survey was a much more qualitative analysis of individual's experiences with the health care system, going further in depth as to why each individual ranked the system a specific way, in addition to collecting general health-related information about the person. These

|   |
|---|
| 1) Please rate the health care system of The United States/ Costa Rica on a scale of 0-10, 0 being extremely dissatisfied (bad/sad) and 10 being very satisfied (good/happy).<br>a) Why did you choose the number you did? (i.e. why so high/low?)  |
| 2) How old are you?   |
| 3) Gender (to be observed, not an actual question)  |
| 4) How frequently do you seek medical care? (i.e. how many times you go to the doctor in an average year?)  |
| 5) What sort of health problems do you have, if any? (For example, do you have diabetes, high blood pressure, cancer?)  |
| 6) Do any of your close family members (mom, dad, siblings, children, grandparents) have any health problems? (For example, do they have diabetes, high blood pressure, cancer?)  |
| 7) Are you employed? If yes, what do you do for work?   |
| 8) What number would you give the Costa Rican/United States health care system knowing whatever you do or do not know about it? (Using the same scale as in question 1)   |
| 9) What type of doctor do you usually go to? (for example: clinic, ER physician, PCP, cardiologist)   |
| 10) How much do you trust your doctor to:<br>a. Always tell you the truth?<br>b. Provide you with accurate, up-to-date medical information?<br>c. Make excellent medical judgments on your behalf?<br>d. Do everything medically that should be done to ensure the best possible result?<br>e. Tell you if a mistake was made about your treatment?<br>f. Put your medical needs above all other considerations, including costs?<br>g. Listen well so he/she understands your needs and concerns?<br>scaling: 5= completely 4=mostly 3=somewhat 2=a little 1= not at all |
| 11) What is the one thing you would like to change about the health care system? If multiple answers, which is the most important change?   |

Figure 2: Extended survey questions. These are the questions that were asked to participants in the longer interviews. Three individuals were interviewed in both Costa Rica and the United States. Question 10 is an adaptation of previous physician trust studies, based on various physician trust scales<sup>18, 19, 20, 21</sup>.

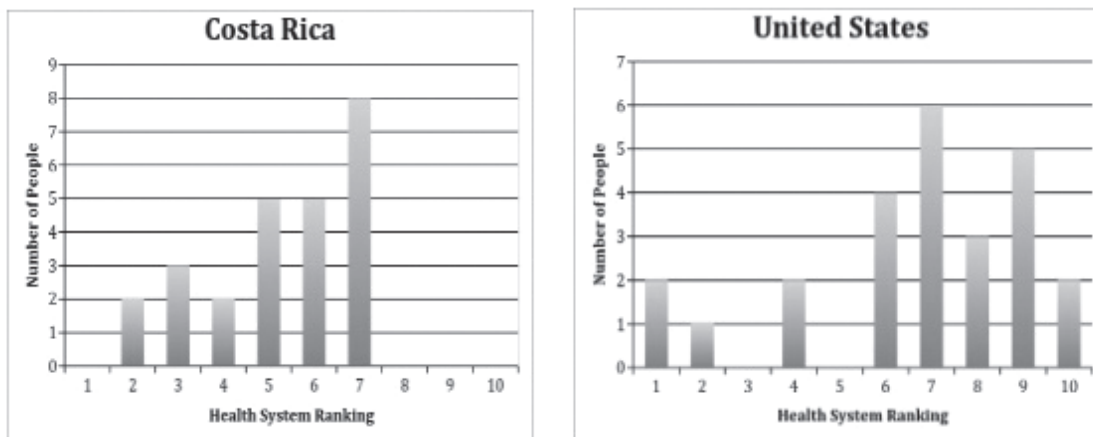


Figure 2: Graphical representation of rankings. These tables summarize the results that were obtained in Costa Rica and the United States. They show the number of people that gave each numerical ranking for their respective country. The United States has more widespread rankings, with people more dissatisfied (thus giving it a 1) but also more satisfied (ranking the system a 10) in comparison to Costa Rica, which was ranked between 2 and 7. It needs to be acknowledged that these results are subjective, in that one person's numerical score of 1 is not necessarily equivalent to the 1 that another person might give. But overall they are able to provide a general view of public satisfaction with health care in each country.

|            | Health        |              | Responsiveness |       | Fairness in financial contribution | Overall goal attainment | Health expenditure per capita | Performance on level of health | Overall system performance |
|------------|---------------|--------------|----------------|-------|------------------------------------|-------------------------|-------------------------------|--------------------------------|----------------------------|
|            | Level (DALE*) | Distribution | Level          | Dist. |                                    |                         |                               |                                |                            |
| Costa Rica | 40            | 45           | 68             | 86-87 | 64-65                              | 45                      | 50                            | 25                             | 36                         |
| USA        | 24            | 32           | 1              | 3-38  | 54-55                              | 15                      | 1                             | 72                             | 37                         |

**Figure 1:** Health system attainment and performance rankings of the United States and Costa Rica, (Adapted from the World Health Report 2000). This table shows the results of the full rankings, according to WHO, for both the United States and Costa Rica. The number values are rankings out of the 191 countries. The US has higher rankings for all categories, except for performance on level of health, which renders its overall system performance below that of Costa Rica. \*DALE stands for Disability Adjusted Life Expectancy. Each of these values in the table comes from a long list of contributing factors. The further breakdown of each section can be found in the World Health Report 2000 Annex Tables 5-10.

|            | Health        |              | Responsiveness |       | Fairness in financial contribution | Overall goal attainment | Health expenditure per capita | Performance on level of health | Overall system performance |
|------------|---------------|--------------|----------------|-------|------------------------------------|-------------------------|-------------------------------|--------------------------------|----------------------------|
|            | Level (DALE*) | Distribution | Level          | Dist. |                                    |                         |                               |                                |                            |
| Costa Rica | 40            | 45           | 68             | 86-87 | 64-65                              | 45                      | 50                            | 25                             | 36                         |
| USA        | 24            | 32           | 1              | 3-38  | 54-55                              | 15                      | 1                             | 72                             | 37                         |

**Figure 4:** Comparison of rankings and participant demographics. This table shows the mean, mode, maximum, and minimum rankings given for both Costa Rica and the United States. Age and gender information about participants is also provided.

$$t = \frac{M_{CR} - M_{USA}}{\sqrt{\left( \frac{\sum X_{CR}^2 - \frac{(\sum X_{CR})^2}{N_{CR}}}{N_{CR} + N_{USA} - 2} \right) \times \left( \frac{1}{N_{CR}} + \frac{1}{N_{USA}} \right)}}$$

$$t = \frac{5.28 - 6.68}{\sqrt{\left( \frac{764 - \frac{132^2}{25}}{25 + 25 - 2} \right) \times \left( \frac{1}{25} + \frac{1}{25} \right)}}$$

$t = -2.289$

**Figure 4:** T-test calculations. A T-test was performed on the results, to determine if there was statistical significance. This is the formula and process that was utilized. A t-ratio of -2.289 with 48 degrees of freedom corresponds to a p-value of 0.02653, which is less than 0.05, and therefore the null hypothesis can be rejected, indicating that the results are significant.

interviews were more encompassing than the previous surveys, taking around 10 minutes per person depending on the individual (the specific questions asked in these interviews are shown in Figure 2). As these interviews were difficult to quantify, their primary purpose was to simply add to the shorter surveys by providing insight as to why individuals are satisfied or dissatisfied with their respective health system. Thus they did not serve as a direct comparison with the WHO rankings, which were based on the five composite indicators: overall level of population health, health disparities and inequalities, level of health system responsiveness, distribution of responsiveness within the population and distribution of financial burden within the population.<sup>1</sup>

**Results**

The data was collected over a two-week period of research in each country (see Figure 3). The short surveys provided some information pertaining to both health systems, indicating that both Costa Rican and American citizens are fairly satisfied with their health systems overall, with an average satisfaction rating of 5.28 and 6.68, respectively, as

shown in Figure 4. A T-test was utilized to determine the accuracy of the hypothesis; specifically, that there is a difference in public satisfaction with the health care delivery systems in Costa Rica and the United States. The null hypothesis, that there is no significant difference between public satisfaction with the health care systems of the United States and Costa Rica, was tested. With 48 degrees of freedom, the obtained t-ratio of 2.29 corresponds to a p-value of 0.0265.<sup>17</sup> This value is less than 0.05, which means that the null hypothesis can be rejected. Therefore, the results of this study are statistically significant, and there is a difference between the public satisfaction of participants with the health care systems of these two countries. Full calculations can be found in Figure 5.

In addition, the longer interviews gave insight into the pros and cons of both countries' health systems. All three interviews for each country were conducted with people of different ages, genders and careers, and yet they exhibited some important similarities in both the United States and Costa Rica. Participants in both countries discussed the reasoning behind their rankings of the health systems, most importantly by elaborating upon the major issues that the systems need to address in order to perform at a higher level. The biggest problem with the Costa Rican system, as indicated by these interviewees, is a lack of efficiency—there are too many issues with the way that the system is run, such as inadequate funding and an insufficient number of physicians, which lead primarily to long wait times that are a major detriment to the health and satisfaction of the population. Meanwhile, the main problem that individuals had with the American system was that it has become more about how to deal with rising costs, rather than focusing on providing care to the entirety of the population. In essence, money is the most important aspect of the United States health system, and the actual health of the population comes second.

The discrepancy between those who receive top level care and those who do not best explains why the United States and Costa Rica are ranked next to each other in the WHO analysis.<sup>12</sup> Even so, throughout this study the actual medical care in the United States was said to be better overall—an aspect that all participants, both Costa Rican and American, said overshadows any other issues with the system. As a result, it was determined that the United States' health system exhibits a higher level of satisfaction amongst participants than that of Costa Rica, although due to the small sample size it cannot be concluded that this is true for the entirety of each country.

**Limitations**

This pilot study, just like all other studies attempting to quantify a subject as complex as health care systems, has some limitations that should be acknowledged. Primarily, the focus group in each country was a major bias factor. First of all, it is difficult to find two exactly similar locations in such different countries. A better, more accurate analysis could have been done with a more even distribution of factors such



as age and gender with a larger sample size. In terms of location, using only one in each country is very limiting, as different places have varying standards of care, public perceptions and overall health institutions. There is also the possibility of potential response bias due to the qualitative rather than quantitative nature of the study.

Most significantly, the small sample size is a limitation, as 25 people is not entirely representative of countries with populations of 300 million in the United States and five million in Costa Rica. Thus, it is not possible to generalize the results to the entirety of the two countries; rather, the intent of the study is the more notable aspect. As with most studies, a larger subject population—specifically by utilizing multiple locations throughout these countries—would have provided more information and made the study more universal. In order to determine an accurate account of health system performance, a much larger version of a study such as this one could be incorporated with the WHO's findings, so as to combine public satisfaction and expert opinion.

## Discussion

The World Health Organization defines health as “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.”<sup>3</sup> Both the United States and Costa Rica have established effective health systems that run very differently from one another, rendering them an excellent choice for further investigation. In contrast to the WHO investigation, this study focused on public opinion in both countries rather than public health expertise to determine the performance of health systems.<sup>2</sup> The intent was to supplement the WHO results rather than replace them, as both public satisfaction and the perspective of experts should be considered together for the best analysis.

This study supplements the WHO report by also attempting to quantify what makes a good, fair and well-performing health system, but through population-based research design. The health system goals created by WHO involving good health, responsiveness to the expectations of the population, and fairness of financial contribution were most extensively addressed in the long interviews but can also be surmised from the basic rankings of the systems provided by short survey participants.<sup>1</sup> In the vernacular of the WHO investigation, this pilot study focused on goodness, indicative of how the health system responds to expectations.<sup>1,2,4</sup> The results demonstrate that although individuals in both countries view their health systems as generally good, there

was a higher level of satisfaction among participants in the United States than in Costa Rica.

As the WHO based its rankings on measures of attainment and performance, the primary measure utilized in this study was a combination of the two, where participants specifically addressed the overall achievement of their respective health system in terms of how satisfied they were with the health care provided.<sup>1</sup> Analysis of public opinion indicates that the United States has a level of attainment and performance that is statistically higher than that of Costa Rica. Yet this may not be practically significant, as the discrepancy between the average rankings, 5.28 and 6.68, is fairly small on the scale from one to ten. Thus, as previously mentioned, a larger-scale study would be much more telling in its results with regards to overall public satisfaction with health care in these countries.

While the WHO analysis is more extensive, this pilot study achieved the goal of providing additional analysis in a complementary capacity. The additional perspective provided by a larger version of this study could prove beneficial to the analysis of health systems in their entirety. In the World Health Organization's own words, “peoples expectations of health systems are greater than ever before,” so it is necessary for the systems to evolve accordingly, but first it is important to determine how to most effectively create positive change.<sup>1</sup> Patient, provider, and institutional characteristics are all necessary factors and must be taken into account for better performance.<sup>15</sup> As a result, it is pertinent to evaluate the opinion of a larger group of individuals on the efficacy of their health care systems, and these methods should be further investigated and possibly incorporated with the WHO report for a more complete analysis of health systems. Public opinion is difficult to quantify, but as portrayed by this study it can provide valuable information about health system performance. Rising costs and lack of access to care are increasingly prevalent in health care systems around the world, so it is vital to analyze the systems in order to determine the causes of these quality issues. Studies such as this serve only as a starting point; much more extensive research must be done in order to further address health system performance, find solutions to these problems, and ensure that systems around the world are acting efficiently and providing high quality care.

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# Barriers to the Elimination of Lymphatic Filariasis in Sub-Saharan Africa

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**This paper examines barriers to the elimination of Lymphatic Filariasis (LF) in Sub-Saharan Africa. Caused predominantly by the filarial worm *Wuchereria bancrofti*, LF infects 120 million people worldwide, with about 40 million people showing symptoms like hydrocele, lymphedema, or elephantiasis. In 2000, the World Health Organization established the Global Program to Eliminate Lymphatic Filariasis (GPELF) with the ultimate goal of eliminating LF by 2020. However, many obstacles persist throughout Sub-Saharan Africa that will make this goal difficult to achieve. This paper relies on a range of research studies to present a comprehensive picture of the current barriers to LF elimination in Sub-Saharan Africa. Species-specific barriers include heterogeneity in the vector distribution, varying ability to pick up and transmit LF and different feeding and resting behaviors. In addition, variations in habitat and weather, urban transmission, and the impact of human behavior are general barriers that contribute to ongoing transmission.**

## Introduction

Lymphatic Filariasis (LF) is a neglected tropical disease that persists in developing countries and impoverished communities throughout Sub-Saharan Africa, Asia, South and Central America. An estimated 1.3 billion people are at risk for contracting LF, with 120 million people currently infected.<sup>1</sup> LF is a parasitic disease that occurs when infective larvae are transmitted to a human host when a mosquito feeds on a human.<sup>1</sup> Three types of filarial worms cause LF: *Wuchereria bancrofti*, *Brugia malayi*, and *Brugia timori*. Of these, *W. bancrofti* is the biggest source of infection, responsible for about 90% of LF cases.<sup>2</sup>

Forty million people infected with LF are disfigured or incapacitated with symptoms like lymphedema (tissue swelling), elephantiasis (skin/tissue thickening), and hydrocele (fluid accumulation in the scrotum).<sup>1</sup> The remaining two-thirds of infected individuals show no visible symptoms of LF, but may experience immunosuppression or renal dysfunction.<sup>3</sup> While LF does not typically cause mortality, the disfiguring symptoms caused by this infection can have significant implications with respect to accomplishing routine tasks and daily social interaction. Those with chronic and disfiguring conditions can alleviate discomfort and prevent secondary infection through rigorous hygiene practices such as washing the affected body parts with soap and water.

The World Health Organization has identified LF as a candidate for elimination due to advances in diagnosis and treatment as well as a greater understanding of its epidemiology.<sup>1</sup> These advances paved the way for a global elimination strategy, and in 1993 LF was identified as one of only six eradicable diseases. The World Health Organization includes LF among the top 17 neglected tropical diseases (NTDs): “a diverse group of diseases with distinct characteristics that thrive mainly among the poorest populations.”<sup>4</sup> The Global Program to Eliminate

Lymphatic Filariasis (GPELF), established by WHO in 2000, views elimination of this disease as a tangible way to improve health outcomes in the developing world.<sup>5</sup> The ultimate goal of GPELF is to eliminate LF by the year 2020.

Treatment for LF involves the administration of albendazole and either ivermectin or diethylcarbamazine and these drugs kill the microfilariae in the blood of an infected individual.<sup>5</sup> The treatment regimen for LF is capable of preventing future infections and stopping the progression of disease in those who are already infected. The current strategy for eliminating LF in Africa is a five-year, uninterrupted mass drug administration (MDA) program delivered to 80% of the population.<sup>6</sup> During MDA, entire populations are treated regardless of the presence of symptoms. Between 2000 and 2012 approximately 4.4 billion treatments were delivered to 984 million people in 56 countries.<sup>1</sup> Prevention of LF also involves mosquito control through insecticide treated nets, indoor residual spraying, or removal of mosquito breeding sites. In addition to MDA, management of morbidity and the prevention of disability among affected individuals are important aspects of LF control.<sup>5</sup>

The topic of LF is important to public health due to the disability it causes in endemic areas. Disfiguration caused by LF has economic repercussions because it debilitates healthy citizens who would otherwise contribute to economic growth.<sup>3,7-9</sup> In addition, the condition can be highly stigmatizing for individuals with chronic disabling symptoms that restrict social interactions.<sup>10-13</sup> Visible manifestations of LF, including lymphedema of the limbs, breasts and genitalia, have profound social consequences.<sup>12-13</sup> The status of LF as a neglected disease means that health education to the populations in danger regarding symptomology, prevention and transmission does not receive the same attention as more prominently-known diseases like HIV/AIDS and tuberculosis.

This lack of education leads to misconceptions and further stigmatizes affected individuals. Increased knowledge of LF will inform healthcare policy, leading to a more effective elimination strategy. The majority of research on LF has focused on individual barriers to elimination. This paper attempts to collate relevant research articles on a variety of barriers in order to provide a comprehensive overview of the most important barriers to elimination of LF.

**Background:**

*Important Terms*

**Threshold Biting Rate (TBR):** the vector biting rate below which infection cannot be sustained in the population.

**Worm breakpoint:** the parasite prevalence below which local extinction occurs.

**Microfilariae (microfilariae):** an early stage in the parasite life cycle that circulates in the bloodstream of the host.

**Monthly Biting Rate (MBR):** the estimated number of mosquitoes that will bite an individual in a community in a month's time.

**Monthly Transmission Potential (MTP):** the number of infective larvae to which a person is exposed each month.

**Annual Biting Rate (ABR):** the average number of vectors that take a blood meal per human host per year.

**Annual Transmission Potential (ATP):** the estimated number of infective larvae that would have been transmitted to a subject at a particular site per year.

**Anopheles gambiae Complex:** a group of at least seven species of mosquitoes that are anatomically similar but exhibit different behaviors. Includes the *An. gambiae sensu stricto* (s.s.) mosquito.

**Exophilic:** a preference of mosquitoes to rest outdoors after taking a blood meal.

**Endophilic:** a preference of mosquitoes to rest indoors after taking a blood meal.

**Anthropophilic:** a preference of mosquitoes to feed on humans.

**Zoophilic:** a preference of mosquitoes to feed on animals.

**Exophagic:** a preference of mosquitoes to feed outdoors.

**Endophagic:** a preference of mosquitoes to feed indoors.

*Mosquito Species*

Several mosquito species are capable vectors of LF and contribute to ongoing transmission. Within the *Anopheles* genus, LF vectors include *An. arabiensis*, *An. gambiae*, *An. merus*, *An. melas*, and *An. funestus* (See table below). *An. gambiae* s.s. is found throughout Sub-Saharan Africa and considered one of the most efficient vectors due to its long lifespan, short larval development period, and other behavioral traits.<sup>14</sup> *An. arabiensis* is also significant due to its wide geographic distribution and behavioral plasticity.<sup>15</sup>

In addition, *Culex quinquefasciatus* is an important vector throughout Sub-Saharan Africa (see map 1). This vector has a worldwide distribution and predominates in urban areas around human dwellings.<sup>16</sup> *Cx. quinquefasciatus* thrives in pit latrines, cess pits, and other areas with decomposing organic matter.<sup>16-18</sup> Although researchers have established the behavioral tendencies of mosquitoes through entomological

studies, most of these species have exhibited variability in feeding and resting as well as an ability to adapt to changing environments.

**Further Analysis of Various Mosquito Species and their Relation to LF**

*Changes In the An. gambiae Complex*

The composition of the vector population in a given area will significantly impact the transmission of LF due to the feeding and resting behaviors described above. A recent study by Derua and colleagues (2012) in Tanzania revealed a change in the relative abundance of mosquito species in the *An. gambiae* complex. *An. gambiae* s.s. was previously the most abundant vector but researchers observed a shift in mosquito composition whereby *An. Arabiensis* was the predominant vector in the complex.<sup>19</sup> This finding could impact the vector control programs in this region and alter intervention strategies for reducing the mosquito population because *An. arabiensis* mosquitoes exhibit different feeding and resting behaviors than *An. gambiae* s.s. Derua's study compared current measures of the *Anopheles* mosquito population with data from the 1980's.<sup>19</sup> In the earlier survey period *An. gambiae* s.s. and *An. arabiensis* were almost equally distributed at 39.2% and 41.9% respectively; data from 2012 revealed a significant shift in composition whereby 76.8% of the sampled vector population was from the *An. arabiensis* species while *An. gambiae* had decreased significantly.<sup>19</sup> These findings are similar to another study in Moshi Tanzania that showed that *An. arabiensis* mosquitoes accounted for 79.5% of the total mosquito population and 99.3% of the *Anopheles* species.<sup>20</sup>

The make-up of the vector population can impact vector control and overall transmission of *W. bancrofti*. Due to the exophagic and exophilic tendencies of *An. arabiensis*, there is a decreased probability that these vectors will come into contact with insecticide treated material like bed nets or walls.<sup>14,19,20</sup> In addition, those mosquitoes that do rest indoors after feeding (i.e. endophilic behavior) have a tendency to avoid surfaces that have been sprayed with insecticide.<sup>21</sup> As a result, control programs that have been predicated on indoor residual spraying and distribution of insecticide treated nets will be less effective.<sup>18</sup> This study also detected an increase in the population of the *An. merus* vector species, posing further problems for control programs.<sup>19</sup> This mosquito is difficult to control with insecticide treated materials and larvicides due to its feeding and resting behavior.<sup>8</sup>

The increased prevalence of both the *An. merus* and *An. arabiensis* vectors has implications for vector control programs and for LF elimination programs at large. In order to effectively control the population of these vectors, their ecology and behaviors must be understood and this information should be applied to the development of control techniques. For example, in areas where endophilic and endophagic mosquitoes predominate, long lasting insecticide treated nets and indoor residual spraying should be implemented. In contrast, in areas where mosquitoes are exophilic and exophagic, vector control programs

| Species                     | Target         | Feeding    | Resting    | Location  |
|-----------------------------|----------------|------------|------------|---|
| <i>An. arabiensis</i>       | Zoophilic      | Exophagic  | Exophilic  | Dry savannah environments across Sub-Saharan Africa |
| <i>An. gambiae</i> s.s.     | Anthropophilic | Endophagic | Endophilic | Humid forested areas across Sub-Saharan Africa      |
| <i>An. merus</i>            | Both           | Exophagic  | Exophilic  | Coastal East and Southern Africa                    |
| <i>An. funestus</i>         | Anthropophilic | Endophagic | Endophilic | Various environments throughout Sub-Saharan Africa  |
| <i>An. melas</i>            | Both           | Exophagic  | Endophagic | Coastal West Africa                                 |
| <i>Cx. quinquefasciatus</i> | Both           | Both       | Both       | Various environments throughout Sub-Saharan Africa  |

Note: these characterizations only describe tendencies, and most of these species exhibit a variety of behaviors





**Map 1:** The global distribution of *Cx. quinquefasciatus* (Source: University of Florida entomology).

should focus on reducing potential mosquito breeding sites.<sup>18</sup>

#### *Infectivity Among Mansonia Species*

Past research on the vectors of *W. bancrofti* in Africa have highlighted the importance of the *Anopheles* species in the dynamics of transmission.<sup>22</sup> Although *Mansonia* species are known carriers of *W. bancrofti* in Asia, they had not been considered as vectors in Africa.<sup>23</sup> However, researchers Ughasi and colleagues (2012) have released the first report since 1958 highlighting the potential for *Mansonia* species to be vectors of LF in West Africa.<sup>23</sup> In the study, 825 mosquitoes were collected in Ghana, 239 (29%) of which belonged to the *Mansonia* species. All of these 239 *Mansonia* spp mosquitoes were identified as *M. Africana*, five of which were found to be infective with *W. bancrofti*. In addition, 388 stored *Mansonia* spp mosquitoes from a previous collection were examined, with a distribution of 144 *M. Africana* and 244 *M. uniformis*. Eleven (7.6%) *M. africana* and 7 (2.9%) *M. uniformis* mosquitoes were found to be infected with the *W. bancrofti* parasite.

The observation that *Mansonia* mosquitoes are LF vectors in West Africa has significant implications for elimination efforts, demonstrating that the transmission system in this region could be more complex than expected. *Mansonia* spp are important vectors, but they have not been factored into the elimination strategy. Because *Anopheles* mosquitoes exhibit facilitation (discussed below), elimination is feasible through MDA alone in areas where they are vectors.<sup>23</sup> The LF elimination campaign in West Africa is based on the assumption that *Anopheles* are the only vectors of *W. bancrofti* in this area.<sup>24</sup> However, the observation that *Mansonia* mosquitoes are LF vectors could present a significant challenge to the GPELF in eliminating LF with MDA alone in this sub-region, necessitating increased vector control efforts.<sup>24,25</sup>

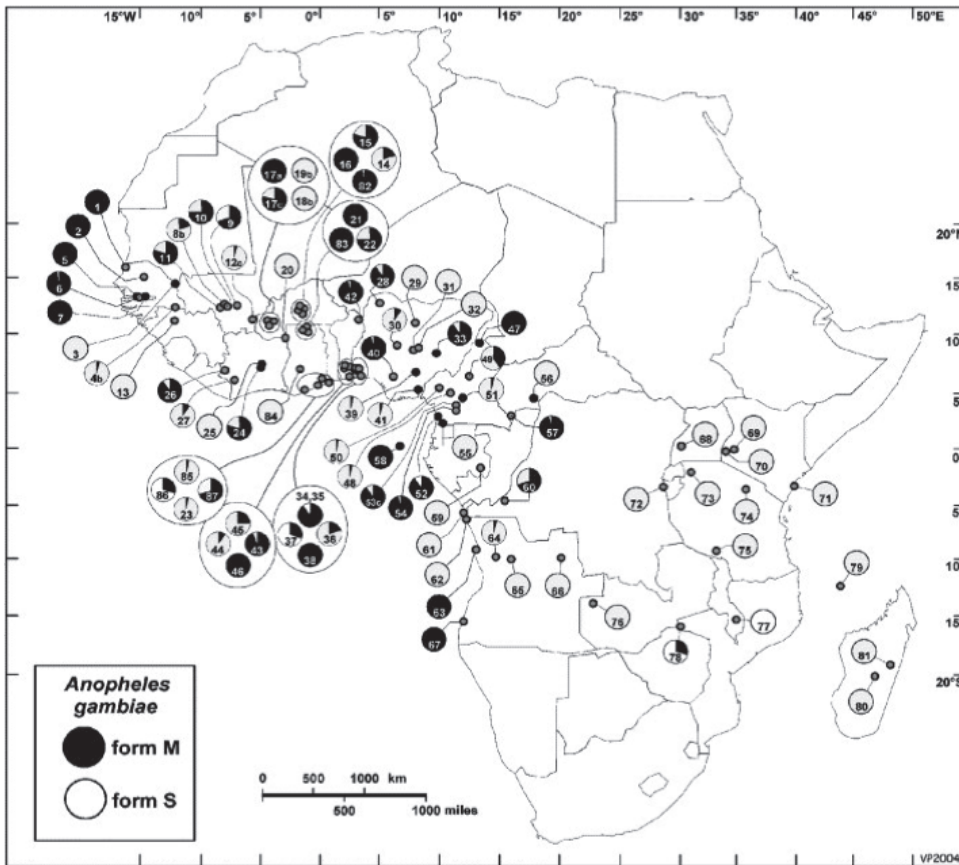
#### *Impact of An. gambiae M Molecular Form on Transmission*

Furthermore, past research has demonstrated varying transmission efficiencies among different molecular forms of *An. Gambiae* s.s. mosquitoes, termed the M and S molecular forms.<sup>24</sup> Researchers have iden-

tified two 'molecular forms' of the *An. gambiae* mosquito, defined according to single nucleotide differences in the ribosomal DNA region.<sup>26</sup> There is significant variation in the distribution of the M and S forms across Sub-Saharan Africa. The M/S distributions are geographically defined and influenced by environmental factors and habitat characteristics. For example, in Ghana, the *An. gambiae* S form is clustered in the 'middle belt' while the *An. gambiae* M form is clustered along the coast and in the Northern Savannah.<sup>25</sup> The M and S forms are associated with factors like elevation, rainfall, and temperature according to an analysis of geographic and climatic conditions. In Ghana, the M form predominates in coastal savanna areas due to the presence of permanent breeding conditions provided by irrigation facilities as well as ponds of water resulting from river run-off.<sup>25</sup> In contrast, the abundance of the S form in the middle of the country can be attributed to the fact that this region is mountainous and forested with lower mean temperatures and the highest recorded rainfall in the country.<sup>25</sup> Although the studies above focus on Ghana, the M and S molecular forms of *An. gambiae* have been identified across Sub-Saharan Africa (see map 3).<sup>26</sup>

Due to the impact of important variables like temperature and precipitation, the *An. gambiae* M form has demonstrated a more latitudinal range in West Africa than the S form and is especially dominant in the hot and arid areas around the Sahel.<sup>27</sup> This research reveals that variations in the landscape impact the distribution of *W. bancrofti* vectors, and transmission dynamics can change drastically between the regions of one country. Mapping the abundance of various mosquitoes and determining their relationship to the *W. bancrofti* transmission is an essential in determining the necessary number of rounds of MDA.

The M form has been identified as the more efficient vector of LF. In areas where the M form is the predominant vector, longer MDA treatment periods may be required to end transmission. For example, de Souza and colleagues (2012) hypothesized that LF transmission in S form-dominant areas may be interrupted after three to five rounds of



Map 2: The 24 countries where M and S molecular forms were identified.<sup>45</sup>



Map 2: Approximate distribution of *An. gambiae* ss in Africa. (Source: University of Florida entomology).

MDA. In contrast, areas with high proportions of the M form or the vector require more than five rounds of MDA, supplemented with vector control.<sup>24</sup> A similar research study by de Souza and colleagues (2010) was aimed at determining the spatial distribution of the *An. gambiae*

molecular forms in Ghana, and their relationship with disease prevalence.<sup>25</sup> The data demonstrated that *An. gambiae* M was significantly positively associated with LF while *An. gambiae* S was significantly negatively associated with LF.<sup>25</sup> As a result, locations with high *An. gambiae* M distribution were observed to have significantly higher LF prevalence than areas where the *An. gambiae* S form was significantly high.<sup>25</sup> Due to the varying efficiencies of M and S form mosquitoes as vectors, researchers must characterize the mosquito population to determine where the M form predominates. This entomological research will inform MDA and allow health authorities to tailor treatment programs according to local vector conditions.

### Diversity among LF vectors and implications for global elimination

#### *Important threshold levels*

The threshold biting rate (TBR) and the worm breakpoint are two threshold levels that have important implications for LF elimination.<sup>28</sup> Mathematical models can be used to determine the appropriate TBR and worm breakpoint necessary to end transmission in a certain population.<sup>29</sup> However, the variation of threshold levels between communities

means that findings from one area may not be generalizable to another area. Therefore, it is necessary to fit mathematical models to site-specific infection data in order to determine accurate threshold levels.<sup>28</sup>

One study demonstrated that ignoring local transmission dynamics will likely lead to the failure of a WHO recommended MDA strategy.<sup>30</sup> Using a model, researchers were able to simulate the impact of the diethylcarbamazine /albendazole drug administration among 80% of the population, in three endemic communities. The simulations of disease transmission demonstrated a wide variation between the communities due to varying transmission dynamics. The probability of LF elimination declines markedly with increased community annual biting rate (ABR).<sup>30</sup> In addition, TBRs varied widely between communities, with high significance levels. Consideration of the TBR, ABR, worm breakpoint is important in determining if current treatment strategies are sufficient. These findings suggest that the WHO-recommended global strategy to eliminate LF ignores variation in local transmission dynamics among communities.<sup>28,30</sup> The authors assert that the simulations “demonstrate the likely failure of a fixed global strategy.”<sup>30</sup> Determining an endpoint (the point at which transmission has reached a low enough level that it cannot continue, even in the absence of drug administration<sup>31</sup>) for an MDA control program should be contingent on site-specific infection data related to these threshold levels. For example, it may be necessary for a community to implement additional rounds of MDA and also to implement more comprehensive vector control due to local data on TBR and worm breakpoints. In order to gain a comprehensive understanding of variation in threshold levels researchers should use predictive models to generate estimates.<sup>30</sup>

#### *Facilitation and Limitation Processes*

In the past researchers have tried to establish the microfilariae levels at which vectors are incapable of picking up and transmitting infection

by studying the density-dependent processes of limitation and facilitation. These processes are tied to the threshold levels discussed above that guide transmission dynamics in communities. Both of these processes are related to the relationship between the microfilariae intake and output of stage three infective larvae ( $L_3$ ).<sup>18,32</sup> In mosquitoes that exhibit limitation or facilitation, the number of infective larvae that develop in the mosquito is not proportional to the number of microfilariae ingested by the mosquito. Limitation is a process in which the output of infective larvae decreases as the number of ingested microfilariae increases. As a result, the output of infective larvae per vector decreases at high microfilariae densities.<sup>18,32</sup> Vectors that exhibit limitation are highly efficient at sustaining transmission even at low microfilariae densities. Therefore, limitation processes counteract elimination efforts by shifting transmission thresholds toward lower values, necessitating more intensive control efforts.<sup>18,32</sup> This process has been observed among *Culex* mosquito populations.<sup>17</sup>

In contrast, vectors that exhibit facilitation possess a cibarial armature that lacerates ingested microfilariae.<sup>32</sup> These vectors are efficient mainly at high microfilariae levels. At low microfilariae densities the cibarial armature substantially reduces the proportion of surviving microfilariae. However, at high microfilariae densities the armature becomes inefficient as it is masked by several lacerated microfilariae, allowing the survival of others.<sup>18,32</sup> As a result of this process, transmission of LF is inefficient and transmission thresholds are shifted towards higher values.<sup>18</sup> Therefore, the measures required to interrupt transmission are less intensive and easier to achieve. The process of facilitation often occurs among *Anopheles* species mosquitoes.

Health authorities should design LF control strategies with a comprehensive understanding of the vector transmission potential in various areas, specifically the processes of limitation or facilitation that these vectors exhibit. Differences in vector capabilities may explain why some MDA campaigns are not successful in breaking the cycle of transmission. An understanding of vectorial capacity at the local level is very important during the implementation of an MDA campaign to determine the characteristics of mosquitoes and inform decisions regarding the number of treatments required to break transmission. MDA campaigns should be tailored according to these findings to ensure that community members receive a sufficient number of treatments.

The failure to eliminate LF in Ghana demonstrates the importance of limitation and facilitation. The assumption that *Anopheles* mosquitoes are the only vectors of LF in Ghana and that they exhibit facilitation has informed the LF elimination campaign and influenced current treatment protocols.<sup>24</sup> Where *Anopheles* mosquitoes exhibit facilitation, elimination may be feasible through MDA alone (i.e. vector control is not necessary).<sup>23,33</sup> It is assumed that low level parasitemia resulting from MDA in *Anopheles* transmission areas will lead to interruption of transmission.<sup>22,33</sup> Despite this, 5-8 rounds of MDA treatment have failed to eliminate LF in some communities in Ghana due to the diversity of vector species.<sup>24</sup> This may be because some species of *Anopheles* (specifically *An. Melas*) exhibit limitation and are thus more efficient vectors.<sup>33</sup> Also significant is the finding that limitation and facilitation processes can both occur within a very small geographic range.<sup>33</sup> These findings reinforce the importance of entomological studies to assess what vector species are contributing to LF transmission. In areas where limitation occurs, vector control is very important to interrupting transmission.

## General Barriers to Elimination:

### *Insecticide Resistance*

In addition to the barriers described above, there are some general barriers that contribute to ongoing transmission of LF in Sub-Saharan

Africa. Vector control is an important supplement to MDA in areas of endemic LF transmission.<sup>34</sup> However, the development of insecticide resistance among various vectors of LF will threaten control efforts if vector control activities do not effectively reduce mosquito populations. On the East African coast, the mosquito species *Culex quinquefasciatus* is the most important vector of *W. bancrofti*.<sup>17</sup> This mosquito has proven to be an efficient vector of *W. bancrofti*, capable of stable transmission even at very low levels of microfilariae in the blood. Results from a study in Zanzibar demonstrated that *Culex* mosquitoes were resistant to all insecticides tested on the island of Pemba, the second largest island of the Zanzibar Archipelago.<sup>17</sup> The median lethal time, or  $LT_{50}$  (time taken to kill approximately 50% of mosquitoes) for mosquitoes from the islands of Pemba and Unguja, when exposed to the pyrethroid lambda-cyhalothrin, demonstrated a significant resistance to this insecticide.<sup>17</sup> In addition, resistance to the insecticides dichlorodiphenyltrichloroethane (DDT) and pyrethroid has been widely observed among *An. gambiae* and *An. Arabiensis* in a number of countries across Sub-Saharan Africa.<sup>17,24,36</sup> In countries that have achieved potential elimination of LF, insecticide resistance will be problematic if LF were to reemerge due to migration or human movement. If mosquitoes are not susceptible to previously effective insecticides, it will be necessary to revise vector control strategies through the development and use of new insecticides.

### *Seasonal Variations*

Fluctuation of climatic conditions also impacts LF transmission dynamics as seasonal variations in temperature, rainfall, and humidity have a direct impact on LF transmission. In some areas, significant variation in *W. bancrofti* transmission may occur within a relatively small geographic area due to differences in environmental conditions like temperature and rainfall that impact vector breeding habitats.<sup>37</sup> Mosquito densities and the proliferation of various mosquito species may be directly linked with seasonal patterns, and this can impact transmission dynamics of LF.

In the Rwegoshora study, the monthly transmission potential (MTP) in the two communities varied seasonally, and fluctuated according to weather conditions.<sup>37</sup> At one study site, a high level of transmission was observed in July-September (shortly after the rainy season).<sup>37</sup> Here, the MTP was 13.5 times higher in May than in November, suggesting strong seasonal fluctuations in transmission. The other study site experienced a similar rise in transmission during and shortly after the rainy season. Conversely, this site experienced virtually no transmission during the dry season. These results demonstrate that transmission does not occur uniformly throughout the year, but fluctuates drastically according to seasonal changes. This seasonal variation must be accounted for when developing a program for elimination of LF by strengthening vector control activities during periods of high transmission. An important aspect of vector control is universal bed net coverage with either insecticide treated nets (ITNs) or long lasting insecticidal nets (LLIN). One study in Uganda demonstrated that LLINs paired with MDA resulted in a sharp decrease in transmission potential<sup>38</sup> and two in Kenya found that ITNs offered effective personal protection against *W. bancrofti* transmission.<sup>39,40</sup> Research supports the effectiveness of ITNs in reducing transmission of LF.

### *Variations In Vector Breeding Habitat*

Transmission intensity may be significantly heterogeneous within a relatively small geographic area due to differences in the habitats available for vector breeding.<sup>37,41</sup> Therefore, mosquito breeding behavior should not be considered uniform, even within a single community. Household location relative to pit latrines and other mosquito breeding sites can impact the transmission potential for the members of the



household.

The diversity of transmission dynamics within a single community was observed in one study conducted by Rwegoshora and colleagues (2007) in rural Tanzania.<sup>41</sup> Although the distance between the first and last village house was only 3.4 km, the data revealed significant variations between homes in regards to ABR and annual transmission potential (ATP). The household ABR for all vector species combined ranged from 920 to 23,353 within the community.<sup>41</sup> Even homes located close to each other showed a significant disparity in ABR and two homes located only 4.6 m apart had an ABR of 7385 and 17,688 respectively, due in part to the presence of a pit latrine on the latter property. Therefore, significant variations in *W. bancrofti* transmission within a relatively small geographic area can be primarily attributed to differences in the habitats available for vector breeding.<sup>37</sup>

Rwegoshora's study has important implications for vector control strategies in LF-endemic areas because exposure to LF is not always homogenous in a community. Mosquito density, transmission potential and the clinical manifestations of LF may vary significantly between households. The abundance of the *Cx. quinquefasciatus* vector species can be attributed to the presence of pit latrines, and the study demonstrated highly variable vector densities based on a home's proximity to a highly productive pit latrine.<sup>41</sup> Therefore, vector control authorities should target pit latrines in vector control strategies where *Cx. quinquefasciatus* is present. For example, treating pit latrines with floating layers of polystyrene beads has been shown to effectively reduce the population of *Cx. quinquefasciatus* mosquitoes.<sup>42,43</sup> Treating pit latrines and other mosquito breeding sites is one aspect of vector control that should be employed.

#### *Transmission in the Urban Setting*

Due to its strong association with substandard living conditions, urban LF is strongly concentrated in areas of low socioeconomic status. This is particularly problematic due to population growth occurring in low-income developing countries: in Sub-Saharan Africa the urban population is estimated to exceed 50% by 2030.<sup>44</sup> Thus, the transmission dynamics of LF in urban areas must be thoroughly understood and considered when designing elimination programs. The dynamic between rural and urban elimination strategies should be studied to inform existing elimination campaigns.

Unfortunately, studies of urban transmission of LF in Sub-Saharan Africa are rare. Two studies in the three major urban areas of Ghana (Bawku, Bolgatanga, and Secondi/Takoradi) demonstrated elephantiasis of the leg and the presence of filarial antigen in several individuals.<sup>45</sup> and other small studies occurred in Jos, Nigeria,<sup>46</sup> Dar es Salaam,<sup>47,48</sup> These surveys are not sufficient to inform policy decisions regarding the implementation of LF elimination measures in urban centers of Sub-Saharan Africa because they are not representative of all urban areas in Africa. Although LF is widespread in rural areas, urban transmission is an important issue especially in small and medium sized cities, which have the largest potential for population growth.<sup>44</sup> Future research should take into account behavioral differences in rural and urban environments, the socio-economic context of urban LF and epidemiological determinants which impact transmission.

In urban environments *Culex quinquefasciatus* are important vectors of LF. *W. bancrofti* has demonstrated a significant potential for urban transmission, primarily because the *Cx. quinquefasciatus* vector thrives in crowded cities with poor sanitation and sewerage facilities.<sup>44</sup> In the past, research and control activities related to LF elimination campaigns have focused on rural areas while urban areas have been neglected.<sup>44</sup> However, urban populations in Sub-Saharan Africa also face a significant burden of LF, due in part to *Cx. quinquefasciatus* mosqui-

toes.<sup>44-46</sup> Due to the rapid growth of cities, LF elimination campaigns should incorporate strategies for the control of LF in urban areas. More research is needed in this area to determine the most effective way to combat LF in the context of an urban environment.

#### *Social Barriers to the Uptake of Treatment*

In addition to the mosquito behaviors described above, human behavior and its impact on transmission dynamics is also an important consideration. Noncompliance with drug regimens can be a significant problem in the implementation of a successful elimination campaign. In order for elimination to occur, it has been suggested that approximately 65-80% of the population must be treated over four to six years.<sup>49</sup> In the interest of global elimination, it is necessary to reduce patient noncompliance and to identify those who are reluctant to take their medication. Researchers have identified fear of treatment as a major cause of noncompliance.<sup>49,50</sup> The medications ivermectin and albendazole may result in unpleasant side effects including nausea, headache, dizziness, fever, malaise, vomiting, decreased appetite and exacerbation of existing symptoms.<sup>49,50</sup> The consequent fear of side effects has been cited as a major barrier to the uptake of treatment. In addition, problems related to the size, number and taste of the tablets were associated with noncompliance and some participants felt that the tablets were too large for children to swallow, and also that the bitter taste and smell elicited nausea.<sup>50</sup> Other problems related to drug uptake include skepticism of the government and international organizations, a concern that the drugs cause infertility, and doubts about drug efficacy.<sup>49</sup> Limited or ineffective health communication in the form of radio spots, posters, or television programs can fuel misconceptions among both patients and health workers alike, contributing to a misunderstanding of MDA and a mistrust of the effectiveness of treatment.<sup>49</sup> Patient noncompliance can be reduced by improving the quality of health messages before and during MDA and also by reducing misconceptions through targeted advertisements and other sensitization activities. Health workers must include effective and culturally sensitive health messaging as a component of LF elimination.

#### Discussion

LF persists in most countries throughout Sub-Saharan Africa despite health campaigns aimed at eliminating the disease. In many areas where mass drug administration has been implemented, LF continues to thrive due to the reasons described in this paper. The GPELF has established 2020 as the international endpoint for LF elimination, but the issues impeding elimination efforts in Africa will prove to be a major obstacle in the coming years. In order to achieve elimination by 2020, health authorities must reassess their elimination strategies, taking into account the heterogeneity associated with LF disease ecology.

In all areas of Africa, capacity building, needs assessments and educational campaigns are vital next steps on the path to elimination. Capacity building includes identifying and training more drug distributors to participate in MDA campaigns as well as engaging local community members to participate in a comprehensive and sustainable vector control program. It also includes fostering collaboration between various government personnel and non-governmental organizations to facilitate the effective implementation of elimination strategies. Needs assessments and monitoring activities can inform these efforts by identifying resource limitations and emphasizing issues that need to be addressed. Finally, educational campaigns are necessary to ensure patient compliance with drug regimens.

In countries where MDA has not interrupted transmission (i.e. Ghana and Burkina Faso) or where MDA has yet to begin (i.e. Liberia), an integrated vector control program should be implemented and

sustained. Vector control should target pit latrines, cess pools, and other sources of human waste in areas where *Cx. quinquefasciatus* mosquitoes contribute to LF transmission. Researchers must analyze the species composition and diversity to determine the best strategy given available resources. A successful LF elimination campaign should be founded on a comprehensive knowledge base regarding local vector composition and transmission dynamics.

Lymphatic Filariasis has been identified as a candidate for elimination in many sub-Saharan African countries but there are many barriers to the successful elimination of this disease. The vector composition in a given area and the variety of feeding and resting behaviors associated with each species can complicate elimination efforts. The abundance of certain highly competent vectors that exhibit limitation processes can result in continued transmission despite MDA. Other variations related to season and habitat impact add to the heterogeneity of transmission and risk of LF within communities. This paper provides a summary of the various obstacles to elimination. Further research can only add to our growing understanding of LF epidemiology and vector characteristics across Africa, allowing us to develop targeted and context-specific interventions.

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# The Realities of Conducting Reproductive Health-based Studies in the Developing World: Cases from Mali & India

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**This field notes article provides an overview of two reproductive health research studies previously conducted in Mali and India and the methodological lessons learned. The lessons learned from these studies were: 1) to effectively emphasize the protocol for the study and the specific timeline to which all study coordinators/partners will adhere; 2) to obtain both written and oral agreements from all the partners to abide by the protocol; 3) to ensure the study tools are approved for use by all study coordinators; 4) to ensure adequate resources are available for use prior to the beginning of data collection; and 5) to provide adequate training to all interviewers and personnel who will be interacting and working with study participants. By following these steps, study investigators in the future will be able to effectively carry out international public health research.**

Social science research is essential to understanding and describing the nature, magnitude, determinants and consequences of reproductive health-related behavior and their associated morbidities and mortalities.<sup>1</sup> According to the World Health Organization (WHO), in order to understand the nature of behaviors and illnesses associated with reproductive health, the consequences of reproductive health problems in social, cultural and economic terms should be explored and understood.<sup>1</sup> The need for qualitative research with a particular focus on exploratory methods is especially necessary when attempting to describe the factors that influence women's health specifically.<sup>2,3</sup> Various sampling approaches, such as location sampling, snowball sampling and respondent-driven sampling, have all been used and explored for the purposes of understanding reproductive health-related behaviors and sexual health.<sup>1</sup> The purpose of this paper is to add to the limited existing literature on methods previously used for the purpose of learning more about women's reproductive-related health behaviors in both Ségou, Mali and Karnataka, India. Furthermore, this paper will provide specific examples of methodological limitations that arose throughout these two studies and how they may be addressed in the future.

## Background & Previous Research:

The overall maternal mortality ratio (MMR) globally has dropped 45 percent since 1990, largely due to public health initiatives driving to reach the United Nations Millennium Development Goal (MDG) of helping improve maternal health globally.<sup>4,5</sup> However, this decrease in overall MMR still lies far off from the goal of decreasing by 75 percent by 2015.<sup>4,5</sup> Every day, approximately 800 women around the world die from preventable causes related to pregnancy and childbirth, 99 percent of which occur in low- and lower-middle income

countries.<sup>4,6</sup> The rates of MMR in these developing regions are approximately fourteen times higher than those of higher income nations with the highest rates seen in Sub-Saharan Africa (510 per 100,000 live births) and Southern Asia (190 per 100,000 live births).<sup>4,6</sup> Most of these maternal deaths are preventable through the use of common medical practices such as antenatal care, skilled birth attendance and educational services for vulnerable populations.<sup>4,6</sup>

Utilization of antenatal care services has been recommended by the WHO as a means to ensure the well-being of mothers and newborns along with the use of skilled care during and after childbirth.<sup>4,6</sup> The utilization of these services along with educational and preventative programs, such as handing out cost-effective educational brochures and community education, has been proven to be effective in preventing detrimental conditions and even death.<sup>7</sup> Previous studies have shown that strong determinants of antenatal care service utilization are religion, traditional or cultural beliefs, women's autonomy or decision-making capability, exposure to media or healthcare messages and the presence of social groups.<sup>8-15</sup> These determinants for antenatal care service utilization were the foundation and justification for conducting both of the studies in Mali and India detailed in this paper.

The need for identifying and sharing the most effective practices to help strengthen health systems has been identified in the Global Health Strategy of the United States Department of Health and Human Services (HHS).<sup>16</sup> HHS states that by promoting the global exchange of the best practices and lessons learned, we will ensure that the evidence supports decisions and program implementation.<sup>16</sup> In a recent study conducted in Mali in 2011, researchers from Emory University aimed to identify and address underlying social determinants of poor maternal health in rural areas through the use of in-home interviews and surveys of other members in the household.<sup>17</sup> While



the study successfully established the importance of mothers-in-law in determining the utilization of maternal health care, the cross-sectional design placed limitations on the study. Some of these limitations were the inability to determine causality (due to being carried out at one point in time and giving no indication of the sequence of events) and also the possibility of recall and social desirability biases due to self-reporting.<sup>15,17-19</sup> In a similar study conducted by UK-based researchers, they stated that the most effective way of understanding social processes and the beliefs they form and influence is through the use of qualitative research.<sup>3</sup> Another study stated that incorporation of cognitive interviewing and in-depth qualitative research allow for the development of scales that capture the element of agency in maternal care seeking.<sup>17</sup>

The purpose of this article is to add to the existing literature on methods that have and have not worked in both low and lower-middle income countries. This paper will present background information on each of the previously conducted studies and their methodologies followed by a discussion of the methodological challenges faced in each of the studies. The study conducted in Mali was discontinued due to its limitations. Both of these studies were conducted and chosen by the author, as they provide ideal examples of methodological challenges international researchers may face. When conducting global health research, specifically in countries like Mali and India, investigators must be tactful in their approach. Sensitive topics such as sexual history, the discussion of miscarriages or abortion, having a history of sexual assault, as well as the level of autonomy or power from familial influence are often considered taboo to discuss, especially with a foreign/external study investigator. This paper will discuss two studies that were conducted and the challenges faced while working with these sensitive subject matters in two different cultures.

### Studying Vesicovaginal Fistula (VVF) in Mali

The World Health Organization has called VVF “the single most dramatic aftermath of neglected childbirth.”<sup>20</sup> Vesicovaginal fistula is a condition seen most commonly in women under the age of 25 in low and lower-middle income nations.<sup>21,22</sup> It occurs when there is pressure necrosis from the fetal head on the vagina and bladder tissues during prolonged and obstructed labor.<sup>23</sup> As a consequence, perforations develop on the walls of the vagina and the bladder, causing a constant and uncontrollable flow of urine from the vagina.<sup>23</sup> VVF is seen in low income nations due to biological, social and economic factors.<sup>21</sup> The main biological factor that affects the development of VVF is the predisposition of African women for having dystocia, or physical blockage during childbirth, due to the relatively narrow structure of the pelvis.<sup>21</sup> This condition is worsened when women are undernourished throughout their childhood and adolescence.<sup>21</sup> In many African countries, girls are married at a very young age due to social pressures resulting in pregnancies that antecede pelvic maturity.<sup>21</sup> Although the occurrence of obstructed labor is most common in younger women, a woman at any age could develop VVF due to an array of factors including large fetal size, malpresentation and intervening diseases.<sup>21</sup>

In most low-income nations, women have little or no access to antenatal or obstetric care, and once they develop VVF, nearly all women go untreated, even though surgery could easily correct the obstetric fistulas.<sup>20,24,25</sup> Due to the smell of urine on their body and clothes, as well as their inability to have more children, the women are often cast out from their communities and left to fend for themselves.<sup>20</sup> By understanding the factors that affect women in the medically under-served populations of rural Africa, treatment and educational programs that address the socially stigmatizing consequences

of the disease could be developed in the hopes of one day eradicating VVF from the developing world.

### Methodology used for Vesicovaginal Fistula Study among Malian Women

This study was a qualitative case-control study based on information collected via personal interviews from VVF patients in Ségou, Mali. This study aimed to determine the possible factors that affect the development of VVF in women at reproductive age. The study population consisted of women who were in Mali and had undergone the VVF correctional surgery through an organization called Physicians for Peace prior to the time of the study. Physicians for Peace is an organization that was established on the premise of working with the underserved populations of developing nations by building long-term, sustainable medical education and training to care for local communities.<sup>26</sup> With this understanding, determining effective means of treatment and prevention education for local communities is critical to the successful eradication of VVF in low income nations. The case group consisted of women in the rural regions of the Tiby cluster in Mali who had undergone the surgery after the creation of the program. The control group consisted of healthy women who were from this particular locality and had not undergone the correctional surgery. There were two surgical missions carried out by Physicians for Peace in 2009, both of which acted as the population base for the case group in this study.

The questionnaire that was to be administered in Mali was developed in collaboration with Physicians for Peace. The goal was to cover 50 percent of the women who received the surgical intervention, which were approximately 30 individuals in the case group and a similar sample size for the control group. Two sets of questionnaires were formulated and sent to the health workers employed by the Millennium Cities Initiative (MCI) and the Millennium Villages Project (MVP) in Mali to determine if the questions were appropriate for the study populations. Once finalized by Physicians for Peace and the workers of MCI and MVP, the questions were to be sent to Mali to be translated into the local dialects.

The final two questionnaires that were developed covered the following topics: social and family life, economic status, social expectations and cultural norms, sexual and reproductive history and medical history. The questions that pertained to sexual assault under the sexual history section were developed as a means to determine if there is a link between the prevalence of sexual assault and the development of VVF, as suggested by previous literature. If a link were observed between the prevalence of sexual assault and VVF, it would have provided justification for additional studies in the future to examine the correlation.

Trained community workers who worked with MCI and/or MVP and resided locally in Ségou were to assist in the interviews of the women selected to participate in the study. Women being interviewed were required to sign an informed consent form in the language they could understand. For the purposes of this study, individuals under the age of 18 were not included in the study as there are many socio-cultural factors, such as power dynamics within the home or limited autonomy, which may have prevented these women from receiving parental or guardian approval. The interview required four categories of information from their participants: information on their social, cultural and economic standing and on their sexual practices.

Once the questions were translated, the health workers of MCI and MVP were to be administered the surveys to the study popu-

lation. After all the interviews were completed, the data was to be sent to the Physicians for Peace headquarters in Norfolk, VA to be translated to English by their employees. Only Physicians for Peace and the health workers in Mali would know the identity of each of the individuals in the study as the interview manuscripts were to be de-identified before being provided to the study investigator. This was to ensure that the identity of the study participants and their private medical history would be protected. The interview manuscripts were then to be sent to the study investigators for further analysis and dissemination of results.

### Utilization of Maternal Care Services during pregnancy in Karnataka, India

In India, approximately 28 million pregnancies take place with 67,000 maternal deaths and one million women left with chronic ill health each year.<sup>27</sup> Maternal mortality and morbidity in India are the result of a confluence of factors, some of which are potentially harmful social norms, attitudes and practices as well as a lack of basic health knowledge.<sup>27,28</sup> As a result of public health initiatives within communities across India, maternal mortality rates have been on the decline since the early 1990s from 560/100,000 live births to 190/100,000.<sup>29,30</sup> However, several of the community-based programs and solutions available have extremely low rates of utilization.<sup>27,28</sup> These programs have not always been scientifically developed to methodically target specific risk factors and address social and structural barriers to behavioral change.<sup>28</sup> There have been several studies conducted in these communities to determine the beliefs and values which act as the basis of their behavior.<sup>28</sup> These studies, however, did not follow the study participants and understand the progression of decisions made during the woman's pregnancy and/or post-delivery. This study aimed to understand women and their immediate family member's views on practices during the pregnancy period; mother-in-laws/mothers as well as husbands were included. There were also new individuals who had not been previously studied: potential mothers. The study of this group provided insight into what women perceive as sociocultural norms prior to becoming pregnant. As previously mentioned by Darmstadt and Tarigopula, the "timely publication of key findings from the formative studies will not only help in disseminating knowledge on behavior change in India, but is also aimed to generate further discussion and research on questions that remain unanswered and thus impede progress in this area globally."<sup>28</sup>

### Methodology Used for Maternal Service Utilization Study in Northern Karnataka

Individuals from three districts in Northern Karnataka—Gulbarga, Bellary and Bagalkot (N=76)—were interviewed about their sociocultural practices, risky behaviors and the prevailing safe practices (practices that women take part in during their pregnancy time period to care for themselves, i.e. attending ANC checkups, taking the necessary prenatal medications, etc.) during the pregnancy period. There were five categories of individuals who were being investigated in this study under which there were four social classes. The five categories were: 1) women who were pregnant; 2) post-delivery (PD) women; 3) potential mothers (PM) as well as their families; 4) mother-in-laws (MIL)/mothers; and 5) husbands. There are four distinct social classes/groups in the three districts of interest: 1) the Kurba's (the farming and shepherding class/caste); 2) schedule castes/schedule tribes (SC/ST; historically disadvantaged people); 3) upper classes (including Lingayats and Brahmins); and 4) single women. Due to the different

social classes potentially having different behavioral practices, two individuals were selected per social class. The only social class that had four less than the rest was the "single women" category as the women did not have husbands to question.

This study used an exploratory research approach and a systematic approach to categorize the data. This allowed the study investigators to make scientifically supported conclusions on the findings and to develop evidence-based interventions appropriately. The data collected from the interviews were used to help guide communication strategies for Behavior Change Communication (BCC) in the field of maternal, neonatal and child health, specifically in Northern Karnataka.

Resource persons (RP, or community health workers employed by the study sponsoring organization) in the local villages of Gulbarga, Bellary and Bagalkot were the primary means of data collection. Brief training was provided to the RPs to ensure they could administer the questionnaires developed by the study investigators. There were a total of five questionnaires developed to address the five different categories of individuals in this study. The RPs identified eight to ten persons from their local region to participate in the study. As the RPs were the points of contact at the individual village level, they were able to identify individuals in their areas accordingly. Each RP was provided a certain inclusion criteria to follow per category. This was to ensure that there were no replications in the type of study participants being used.

Once all 76 individuals were selected, the RPs were provided with a schedule in which they met with each of their study subjects a total of three times with a fifteen day interval between each visit. The initial consultation consisted of an in-depth interview, after which the two following visits served as a check-in and wrap-up session. After each round of interviews, the data was transcribed and sent back to the head office to be coded and entered into the database. At the conclusion of data collection, the data was coded for overarching themes and reported to the community.

### Discussion

There were several aspects of both studies conducted that yielded valuable information for consideration in future studies. In this section, some of the lessons learned from both studies (Figure 1) and how they may be resolved in the development of future studies are discussed. Some of the issues were: 1) communication problems with international partners; 2) social and cultural norm barriers; 3) a truncated timeline to conduct the study; 4) lack of substantive training for RPs; 5) language barriers; and 6) interview tool discrepancies.

### Communication Problems

There were several components in the Mali project that required cooperation from the international partners including Institutional Review Board approval by the government of Mali for the purpose of data collection. Partnering with in-country organizations presented challenges due to language barriers, limited or restricted access to technology and physical barriers between the subjects and the study investigators. The partnering organizations consisted completely of non-English speaking individuals, which slowed down the process of communication in each step required to conduct the study. The time restraints that were put in place by the study investigators were also not effectively conveyed due to communication difficulties. Translating everything from English into French initially seemed menial, but as the study progressed, resulting in large documents and detailed emails, it took extensive periods of time to translate to and from En-

glish. Access to technology in Mali was also an issue, as the partnering organizations did not always have access to email or computers. Additionally, the primary method of communication used during the study was email, which presented challenges in coordinating a project discussed only remotely rather than in person. The absence of interpersonal communication contributed to the delay in achieving project milestones.

### Social and Cultural Barriers

Social and cultural norms may have played a role in the delay and/or prevention of obtaining detailed responses in both of the studies. The questionnaires and interview tools were developed specifically for the purposes of these studies. They covered subject matters of a sensitive nature and required close consideration and patience to work with the study participants. In the Mali study, questions regarding reproductive health history, sexual assault and cultural practices may have prevented the organizations from agreeing with the methodology of the study, as in many cultures these subjects are rarely discussed. In the India study, this may also have been the case with some of the families, as families often do not disclose power dynamics in the household and women's reproductive health history. Also, husbands in the India study often were reluctant to share or were unaware of the practices and services their wives availed during visits with a medical professional.

### Timeline Restraints

Working with a condensed timeline to conduct the study in Mali also played a role in limiting the ability to collect data. At the beginning of the study, a timeline was developed to ensure all activities required to complete the study were given ample time to be carried out. But as the study progressed, issues began to arise, and the timeline was not followed. In order to allow data collection to begin, Institutional Review Board approval was required from both the Malian government as well as from the institution the author was a part of at the time. This step was in the original timeline but as the international partners presented an ambiguous protocol on the process of Mali IRB submissions, problems arose. The process of determining the exact IRB protocol took five months for study investigators to uncover during which time the proposed timeline was completely offset. Therefore, an executive decision was made by Physicians for Peace and all the study investigators to discontinue the study at the time, resulting in no collection of data.

### Lack of Training

In the India study, the RPs who conducted the interviews did not have adequate training in how to execute the interview process. The interview manuscripts made it evident that the style of interview conducted by the RPs did not address the type of information needed for the purpose of creating communication tools for the community. In order to create effective communication tools, the study investigators needed to have more insight into the individuals' lives, meaning more in-depth interviews. However, the RPs did not inquire about all the categories determined by the investigators as important indicators for communication tools. The information obtained from each of the interviews varied in the type of information collected, as there was no standard set among the group of interviewers. The style of questions asked by the interviewers was also a source of response bias in the interview process. It was clear the RPs were looking for specific answers and were therefore asking leading questions to obtain those answers from the respondents. After reviewing the interview manuscripts, it

was also evident that the interviews consisted more of the RPs speaking and the respondent providing short answers rather than providing in-depth responses. The style of the interview was not a narration from the respondent but rather just a simple question and answer session with no in-depth explanations or descriptions for some of the key questions. There was also a lack of fluidity in the information provided and it appeared more as broken thoughts.

### Language Barriers

As mentioned previously, communication was a major influence on the success of our studies. In the Mali study, having only one translator resulted in the reduced momentum of data collection. We also relied heavily on this individual to ensure that study methodology, timelines and study milestones were explained in detail to the international partners. This was a limitation as this individual did not have any formal research background and was solely responsible for conveying all the information regarding the study. Language differences were also a limitation in the India study due to dialect differences and interview manuscript translations. RPs were responsible for interviewing individuals in their local regions to help assist with language differences. This, however, posed as a challenge for transcribers as not all of the individuals were familiar with different dialects and their underlying meanings. Therefore, English transcription was very poor and the contexts of the answers were not clear in many instances. This also led to the interview analysis process becoming very tedious, caus-

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ing it to take much longer to analyze than anticipated.

### Tool Discrepancies

The last major issue that arose was due to discrepancies and difficulties in inquiry about sensitive issues with the interview tools. In the Mali study, there were issues when developing the interview tool due to the sensitivity of the inquired information. The main concern and comment made by the Malian IRB was how we were determined to inquire about incidences of sexual assault among these women and the inappropriateness of asking about such subject matters. This was also one of the main reasons we had much difficulty obtaining IRB approval in Mali. In the India study, many members of the research team who developed the interview tools were unsure what the real expectations of the study were. The questions were extremely broad and had no real direction.

### Future considerations

A major future consideration for researchers who wish to conduct studies in low and lower-middle income countries which focus on reproductive health is allowing ample time to conduct such in-depth studies. There are many components that need to be considered and accomplished before data collection can begin. Therefore, planning for delays in the execution of data collection will benefit study investigators. Revisions of the interview tools may also need to be considered due to the sensitive nature of the questions that may be asked. If researchers are able to pilot the interview instrument, it will benefit them in the long run, as it will allow for study investigators to determine the nature of the responses that they may obtain. Variation may occur in the types of responses which are obtained based on different interviewing styles, therefore piloting the tool may assist in understanding areas which may need improvement.

Hiring individuals in the locality where the study is conducted and providing training on the interview/survey tool to these individuals will also help with carrying out the necessary tasks in the local region. This may also be an effective strategy to adhere better to the overall timeline. This strategy would be more effective rather than assigning work to individuals who may not or cannot devote the time needed to execute each step. Since international study designs often call for the help of organizations who partake in other programs, it is difficult to demand that their time be spent solely on conducting just one

study. Therefore, reliability and accountability are essential to carrying out international projects with a sensitive nature such as the studies mentioned in this article. Consequently, working with partnering organizations that not only have a reputable name but also have been recommended by other individuals within their own country is essential to the success of a study.

### Conclusion

This article provided an overview of two reproductive health research studies previously conducted by the author in Mali and India and the lessons learned. The author chose both of these studies as they provide ideal examples of methodological challenges international researchers may face. Some of the lessons learned from these studies were: 1) provide direct emphasis of the study protocol and the specific timeline to all individuals working on the study; 2) to obtain both written and oral agreements from all the partner organizations to abide by the protocol; 3) to ensure the study tools are approved for use by all stakeholders; 4) to ensure adequate resources are available for use prior to beginning of data collection; and 5) to provide adequate trainings to all interviewers and personnel who will be interacting and working with study participants. This being said, qualitative research is essential to understanding reproductive health-seeking behaviors in women in low and lower-middle income countries. As one of the two studies detailed in this paper was unable to be carried out as a result of several of these challenges, utilizing the lessons learned from this study and remembering that communication is crucial to the success of any international study, and study investigators in the future will be enabled to effectively carry out international public health research.

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# The Health Needs of the Fa'afafine in American Samoa and Transgender Research Methodology

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Since the early years of anthropological ethnography, the Samoan third gender community, fa'afafine, has been the subject of research about theories and etiologies of gender and gender behavior. However, few studies have assessed their health needs. Without the necessary data, solutions to health problems in the fa'afafine community are unclear. This paper seeks to discuss this issue and offer suggestions for how research can be designed to better assess fa'afafine health needs.

First, this article will review current research on fa'afafine communities, highlighting how many methodologies carry ethnocentric bias and focus on etiology instead of the health data needed to create interventions for the community. Second, this article will discuss the health needs that arise from the cultural context of the fa'afafine with a focus on violence, HIV and sexual health, institutional recognition of gender variance and maternal and child health. Finally, suggestions will be provided for a third gender affirmative methodology that is inclusive of fa'afafine but also applicable to other gender variant communities globally. These recommendations include (1) structuring research appropriately to explore variation in these groups, (2) restructuring gender variables, (3) conducting community-guided and community-serving research, (4) considering historical dimensions of fa'afafine, gender variant and transgender marginalization and (5) including gender variant health issues in women's health practices.

This paper was written based on a review of secondary sources as well as the author's field notes and observations as a professional working on a project in the Department of Obstetrics and Gynecology at the Lyndon B. Johnson Tropical Medical Center in Tutuila, American Samoa.

## Introduction

There have been many anthropological studies examining the cultural and social contexts of the fa'afafine since initial ethnographies in the 1930s. In Samoan culture, there are three distinct genders, man, woman and fa'afafine. Commonly described as a third gender category, fa'afafine translates as, "in the manner of a woman". It describes individuals who are born anatomically male, but are culturally identified as women. However, data on fa'afafine health needs and consideration for cultural changes in recent years are lacking.

A review of literature on health concerns of the fa'afafine reveals that studies were mostly concerned with gender variant behavior, etiology and Western hypotheses of male androphilia (homosexual behavior). There are no studies that focus directly on the health status or needs of the community. This paper will discuss fa'afafine health needs and common research recommendations. These topics necessarily involve addressing politics in health research and recognizing that Western methodologies do not always fit the social contexts of the medical needs of communities in developing nations. Information is drawn from secondary sources and the author's ethnographic field notes and professional observations gathered on Tutuila, American Samoa, to discuss the gaps in current research and pose more questions. Finally, the paper will offer recommendations for a methodology that is culturally appropriate for fa'afafine and other gender variant groups.

## Terminology

It should be noted that this article uses the term gender variant to describe communities, identities and behavior that do not fit binary understandings of gender. Gender variance is a broader term that is more inclusive of different cultural gender identities. The term transgender is used in the U.S. to define any individual that identifies as a gender that does not match the one they were assigned by society. In Samoan culture, fa'afafine is not culturally defined in the same way as transgender people are in the U.S., but transgender is often used as a cross-cultural cognate both colloquially and professionally. So "gender variant" is used to acknowledge cultural differences, but also to relate and discuss the similar experiences between these communities.

**American Samoa:** American Samoa is an unincorporated territory of the U.S. located in the Samoan Archipelago, a group of seven islands. Tutuila is the main island of the U.S. territory. The other islands, including Upolu, the most densely populated, and Savai'i, the largest by land mass, are part of the independent country of Samoa (also called Western Samoa). The estimated population on Tutuila is 62,600.<sup>1</sup> About 95% of American Samoa's population is on the island of Tutuila, which is home to the only hospital in the territory, Lyndon B. Johnson Tropical Medical Center. About 60% of the population lives in poverty and are dependent on government assistance.<sup>1</sup> The World Health Organization's Non-Communicable Disease report states that the two main sources of income on the island consist of tuna can-

ning and U.S. government assistance.<sup>1</sup> According to the WHO, LBJ Medical Center had 49 practicing physicians, 15 dentists, two pharmacists and 127 nurses in 2003.<sup>2</sup> Other health institutions include the American Samoa Department of Health and local pharmaceutical dispensaries. The island's population is mostly American Samoan and Western Samoan, with communities of Chinese and other Polynesian immigrants. There are currently no estimates of the fa'afafine population in American Samoa.

**Defining Fa'afafine:** The term fa'afafine is a third gender category in Samoan culture that encompasses a variety of individuals. Traditionally, the term describes biological males raised as females (and addressed with female pronouns) after their family recognized feminine qualities in their behavior. Generally, fa'afafine display some form of feminine behavior or gender presentation and take on social roles belonging to women. However, the extent and manner of their gender presentation varies and fa'afafine have male gender roles as well.<sup>3</sup> Though traditionally defined as women by society, they are a heterogeneous group in which some pass for women; others only adopt elements of female presentation and still others are more masculine.<sup>4</sup> Some may dress as women full-time, part time, or only adopt certain aspects of female appearance, like makeup or nail polish. Some fa'afafine identify themselves more as men. It should also be noted that fa'afafine may not always present their gender in the same manner day-to-day. Many identify as women, but most would define themselves as biologically and socially distinct from women.<sup>3</sup> Traditionally, their gender roles have included domestic labor (as with biological females) and the parenting of orphaned children or children that community members have no means to care for.<sup>3</sup>

Many studies assert that fa'afafine form relationships solely with men.<sup>3,4</sup> Fa'afafine consulted during the course of this project had relationships with men, women and other fa'afafine. While many fa'afafine would consider relationships with other fa'afafine lesbian in nature, such relationships (both fa'afafine and same-sex female relationships) do occur even though they are not socially accepted. These relationships illustrate how modern sexual behavior contradicts traditional Samoan views of relationships, which does not recognize same-sex female relations.

In American Samoa, there is a gender variant category encompassing biological females, though this group is not socially recognized by traditional culture. They are locally called tomboys and generally partner with women. Many of the biological women consulted had relationships with tomboys after getting out of abusive relationships with men. Culturally, this is not considered lesbianism by American Samoans, and same-sex female relationships occur, albeit discreetly. Some scholars have speculated that this more modern fluidity of sexuality and gender in Samoan culture is a product of globalization.<sup>5,8</sup> That is to say that liberal Western secular values of sexuality and gender expression have been adopted by many Samoans, which contradicts the more conservative religious values so integral to the culture. This is partially true, in that fa'afafine partake in the sexualized gender expression of Western drag queens. However, fa'afafine simultaneously seek to keep the fa'asamoa (the Samoan way). For example, they take great pride in the annual pageant which involves Western drag queen lip-synching performances and runway fashion shows. This event is televised on the local network and the village of the winner takes pride in the victory. In addition, the fa'afafine the author consulted with were all active in their church or religious communities, participated in traditional dances and rituals and described themselves in distinctly different terms than drag queens or LGBTQ. In this case, globalization brings both change and adherence to tradition. Despite

their social visibility, how fa'afafine are regarded or accepted in Samoan culture today is contested as Samoan religion and culture come into dialogue with Western values. Therefore, the research is limited on the current social acceptance, social status and health status of fa'afafine.

### Reviewing Current Research on the Fa'afafine Community:

In qualitative research, the narratives of the marginalized status of fa'afafine are inconsistent because cultural acceptance is currently being debated among Samoans. Fa'afafine are assigned domestic and child-care roles from pre-colonial Samoan cultural norms, and simultaneously, face misogyny and homophobia. This stems from modern globalization and the change in sexual/gender norms shaped by Christianity, both historically and today. Currently 98% of the Samoan and American Samoan population is Christian.<sup>6</sup> Many sources state that globalization changed the fa'afafine gender performance, which clashed with traditional gender norms and thus introduced homophobia.<sup>7,8,9</sup> They state that fa'afafine have adopted radically different presentations of gender from the western drag tradition, which brings increased public anxiety to Samoa. They argue that culturally this has fostered an urge to catalogue and discriminate against these new categories of behavior and gender expression.<sup>7</sup>

The complexity of cultural acceptance is exemplified in the current legal context in Independent (Western) Samoa, where recent reports indicate an increasingly homophobic national climate.<sup>7</sup> In 2013, homosexual relations were made illegal, and same-sex marriages remain legally unrecognized. This legal ban stemmed from debates in July 2006 when two reverends put out a public call for a ban on homosexuality, sparking a national discussion that mobilized the 2013 ban. It is unknown how the ban affects fa'afafine sexual relations. No legal precedents have been set, and Samoans do not consider relations among fa'afafine to be homosexual. As a result, social acceptance in qualitative research is conflicted.

Clinical and quantitative research on fa'afafine are focused on the development and socio-behavioral patterning of their gender and lacks useful data for health and social services planning. Studies tend to examine birth order and family structure of fa'afafine, genetic vs. behavioral explanations of the occurrence of fa'afafine, the nature of fa'afafine tendencies to care for children, the relationship between an individual's gender role and the development of homosexual behavior and the child and adult patterning of gender atypical behavior.<sup>3,4,9-18</sup>

Many authors are interested in investigating the biological basis for male androphilia (male-to-male sexual relations) in a non-Western population to make inferences about its evolution and etiology. For example, one study investigates the birth order of fa'afafine to find that they have more siblings on average. The author interprets this as support for a biological and evolutionary basis for male androphilia.<sup>8</sup> Another study uses quantitative methods to suggest a higher sibling ratio among fa'afafine, particularly more female siblings.<sup>17</sup> One article presents evidence against the hypothesis of social construction as an origin of fa'afafine behavior.<sup>3</sup>

Another study argues that fa'afafine evolved in Samoa as an adaptation for promoting indirect fitness. This means fa'afafine help ensure reproductive success of the society by caring for children that they did not produce.<sup>10</sup> Another article tests the kin selection hypothesis (i.e. that male androphiles were naturally selected to be helpers of kin with fa'afafine).<sup>11</sup> Barlett finds that fa'afafine, who she calls "androphilic males," exhibit more cross-gender behaviors in childhood.<sup>4</sup> Though these studies provide data on behavior, data regarding the social circumstances and health needs of the fa'afafine community are still lacking. Such data is needed by service providers.



However, previous studies do provide three useful findings for service providers and public health efforts. For example, one study dispelled the traditional cultural myth that individuals who are selected to be fa'afafine belong to families with too many male children, finding that most fa'afafine have multiple sisters.<sup>14,15</sup> Another article also estimated the fa'afafine population in Independent Samoa (between 1.43% - 4.65%), which could be useful for quantifying populations for interventions.<sup>15</sup> Another study discusses the heterogeneity of gender expression, gender identity and sexuality of fa'afafine; it also recognizes that fa'afafine can change their gender expression over time or socially behave as women intermittently.<sup>4</sup>

Though these findings are helpful, these studies do not suggest guidelines for working with this population. These articles neither recommend nor outline a plan of care that addresses the health concerns or wider social concerns of the community.<sup>3,4,9-18</sup> These studies also use heterosexual males as a comparison group for fa'afafine, which inaccurately frames them in a Western paradigm as homosexual or "androphilic" males.<sup>3,4,9-18</sup> This misrepresents understandings of this group, which should be categorized by gender, and not sexuality. The lack of quantitative or qualitative data on fa'afafine health issues and research biases reinforce the marginalization of this group, which leave professionals and researchers with no framework to adequately work with these populations. In the absence of assessments that measure the social and health needs of this community, what is known about the health needs of this population? The following section discusses some possible areas of need recorded in field notes from observations and discussions with people on the island.

### Fa'afafine Health Needs in American Samoa

Health issues that affect the general population in American Samoa include high prevalence of noncommunicable diseases, or "lifestyle diseases". Cancer, alcohol dependency, obesity, diabetes and high blood pressure are common. 62% of the population are physically inactive.<sup>1,19-21</sup> However, injuries due to road accidents and domestic violence are on the rise and pose significant health burdens.<sup>19</sup> In other gender variant populations, we know that gender identification can affect health behavior and health access and would therefore require different strategies to achieve optimal health outreach and intervention.<sup>22</sup> In American Samoa, in addition to health concerns affecting the general population, specific issues that affect the fa'afafine community include lack of institutional recognition of third gender status, violence, HIV, sexual health issues and maternal and child health concerns. These issues have implications for outreach and prevention. They will be discussed in the following section along with qualitative accounts from field notes collected while working in American Samoa to highlight possible health issues for the fa'afafine community in the absence of a formal assessment of health needs. Common themes that arose from talking to fa'afafine can help policy-makers better formulate health initiatives by highlighting areas of need.

#### *Institutional Recognition of Third Gender Status*

One issue that poses challenges to community research and health initiatives for fa'afafine is that health institutions do not record third gender status and thus fail to track health status specifically for this group. Medical records do not have a separate gender category for the fa'afafine; instead they are categorized as males. The inadequacy of intake forms to capture gender variance has been noted in transgender communities in the U.S. as well.<sup>22</sup> Thus, using the hospital for health data on the community is problematic in tracking health outcomes and service utilization. The hospital and department of health in American Samoa currently do not have any community initiatives,

programs or services that specifically address the health needs of the fa'afafine community. This is a common global trend faced by gender variant people who find that health care services are not suited or tailored to their needs.

#### *Violence*

The violence fa'afafine experience is tied to male privilege. Samoa is a male-dominated culture in which women are socially disadvantaged.<sup>7</sup> Fa'afafine have increasingly experienced public discrimination. Inaccurately referred to as homophobia, this de novo misogyny is part of a pattern of oppression and marginalization of women and non-male genders that is pervasive in the culture. It is not only the marginalization of women but also of third-gender women.

Stemming from this marginalization of women, violence is a psychological and physical reality for fa'afafine. Violence serves to isolate the fa'afafine, disrupt their access to and utilization of health services and may be responsible for certain health outcomes. However there are currently no data on how fa'afafine experience interpersonal, sexual or domestic violence. On the other hand, it is known that domestic violence is a major issue for biological females. Domestic violence cases are increasing and are responsible for many cases of hospitalization (coma, deaths, injuries, harm to fetus, etc.).<sup>1</sup> After examining patient charts from the labor and delivery unit, it appears that trauma to fetus is a common complication tied to domestic violence. No studies exist on how domestic violence affects fa'afafine, although their experience is related to the same cultural values of male privilege that impact women.

Networking with the Society of Fa'afafine in American Samoa (SOFIAS) created the opportunity to hear about and participate in discussions regarding the social safety of fa'afafines as members of the community. The author, a transgender woman, was constantly asked if anyone had given her trouble during her time on the island and advised to call any community members if she "ran into trouble," which had a subtext of violence. Many fa'afafine shared experiences of harassment out in public alone. They also frequently mentioned that bullying of fa'afafine youth is a major issue in the local schools. All of the fa'afafine the author consulted had experienced harassment. They also expected and were prepared to deal with potentially aggressive situations. These fa'afafine always traveled in groups and served as a network for each other. They also were mindful of how they avoided confrontation. Temukisa, one member of SOFIAS, stated that she tends to stay close to family or friends and avoids going out alone. She explained that fa'afafine face verbal, physical and sexual harassment (as noted in other research).<sup>22</sup> She advised, "You have to stick up for yourself. You have to put up a fight. Some people have no respect at all." The author encountered a similar sense of social danger and harassment during the project. According to the biological females with whom the author spoke, this violence and threat of violence occurs in similar ways to them, though it is more frequently experienced by fa'afafine. A woman never travels alone and is socially encouraged to stay close to the family unit. Therefore this social marginalization is more akin to the harassment of women than homophobia. Violence is a commonality that socially unites women and fa'afafine, as both groups tend to look out for each other and stick to each other's company.

Other undocumented health concerns for fa'afafine (related to violence) are suicide and deteriorating mental health. Marginalization, social violence and the poverty on the island compound mental health issues. Currently data is needed for suicide within the fa'afafine community or fa'afafine youth. Generally, suicide is particularly prevalent amongst youth in Samoa at a rate of 11.7 per 100,000 (compared to

10.9 among U.S. teens).<sup>19</sup> In addition to these general youth health issues, fa'afafine youth live in a hostile social environment and experience an emerging pattern of ostracizing by their peers.<sup>7</sup> These factors may serve to tilt fa'afafine into life situations and behavior that put them at risk of other health issues.<sup>22</sup>

#### *HIV and Sexual Health*

There are no prevalence and incidence estimates of HIV (or other sexually transmitted infections) in American Samoa. It may be a serious health issue for the fa'afafine community, who may be socially more at risk as seen with other gender variant populations.<sup>22, 23</sup> SOFIAS has recognized HIV as a potential threat to their community and has mobilized awareness campaigns on the island. Condom usage is low and access varies with imports to the island. Data from the Youth Risk Behavior Survey reported that 65.5% of females and 54.3% of males in American Samoa did not use a condom during their last sexual intercourse.<sup>24</sup> In addition, 38% were never taught about HIV or AIDS infection in school.<sup>24</sup> Sexual activity outside of marriage and condom use are contentious topics that sometimes conflict with religious beliefs. Fa'afafine discussed that obtaining condoms is often met with assumptions of promiscuity, which is compounded for fa'afafine whose sexual relations are contentious in Samoan culture. Therefore, fa'afafine face stigma in accessing preventive services.

Another cultural barrier to treatment and prevention is also experienced by biological women. After working in the hospital, the author noted that chlamydia was prevalent on the island, despite the available treatment at the hospital. Samoans and palagi (off-islander) clinicians stated that many families have joint bank accounts controlled by the matai (chief), the eldest male in the family. To access the treatment, one would have to request money from the matai; such actions are often met with stigma and blame. Many women never get treated, leading to the increased prevalence of birth complications. It can be inferred that the stigma for HIV could manifest in a similar fashion for fa'afafine, who would have to ask the matai for funds to get tested or treated. This could be a tremendous cultural barrier to services.

The fa'afafine the author consulted also provided insight into paths of transmission for HIV and STIs. Some of the fa'afafine had disclosed that they had sexual contact with foreign men and married men. Additionally, many Samoan men cheat on their wives and take a fa'afafine lover after a divorce. Fa'afafine are directly impacted by the sexual health behaviors of men. Given these paths of transmission and barriers to accessing condoms, HIV and other STIs pose a significant health challenge for this community. Future research needs to determine the prevalence of STIs and HIV and monitor them within this community.

#### *Maternal and Child Health*

Fa'afafine are commonly viewed as good parents to children and are expected to take up the role of proper child-care, especially in rural communities. This motherhood role has been romanticized in previous literature, obscuring the fact that some fa'afafine migrate to urban communities to escape this responsibility.<sup>7</sup> However, the cultural expectation is still strong, and many fa'afafine still become mothers and take pride in such customs. Some of the fa'afafine the author consulted were mothers and were given children when they were older. The villages in which they resided both recognized and respected their role as primary caregivers for their children. Notably all of these fa'afafine were also single parents, perhaps due to the tendency of men to exploit them for money and pleasure.<sup>7</sup> This phenomenon is compounded by the fact that marriages to fa'afafine are not yet legally recognized.<sup>7</sup> Because the fa'afafine often take on caretaker roles, they could benefit from health and social welfare programs aimed at assisting single

mothers and older caregivers. The methodology of maternal and child health projects must recognize these non-female individuals as commonly the sole providers of care and support for some children. Public health interventions or research aimed at mothers and children need to take into account that some mothers may be neither biologically female nor genetically related to their children. Additionally, fa'afafine are expected to contribute disproportionately to the household since custom dictates that they should do women's work but be better at it than women.<sup>7</sup> Therefore programs, interventions and policies that seek to affect change in women's domestic sphere, maternal and child health and/or childcare should include fa'afafine in their strategies.

#### *Transgendering research methodology*

In order to better address the health needs of the fa'afafine communities, five changes in research methodology should be implemented; these recommendations may also be applicable to other gender variant groups. Gender variant research in U.S. transgender communities has moved from mental health etiologies to more public health community based research/interventions in recent years.<sup>23</sup> However, when it comes to the fa'afafine in Samoa, research is still preoccupied with psycho-behavioral etiologies and views fa'afafine as a condition. The gaps in the literature, the biased methods and frameworks of existing research and the growing need for third gender health research by pacific nations highlight the utility of these following recommendations.<sup>25, 26</sup> Other authors are cited alongside recommendations made by the author of this paper. These recommendations are modeled on the feminist epidemiology of Marcia C. Inhorn, a medical anthropologist.<sup>27</sup> Feminist epidemiology, an examination of antifeminist biases in research on women's health, is an alternative epidemiological framework which would seek to address gender, race and class in public health prevention. Inhorn's work has implications for health practice with transgender or gender variant communities, which structure the following recommendations.

#### *Recommendations*

##### *1. Structure research appropriately to explore variation in third gender groups*

Research involving third gender or gender variant people should focus primarily on those communities' issues and not conflate the subjects with other groups.<sup>28</sup> As stated previously, many studies of fa'afafine use heterosexual males as comparisons. Similarly, most research in the U.S. includes gender variant people in analyses of other sexual orientation groups.<sup>29</sup> For instance, studies of HIV risk include transgender women in samples of men who have sex with men.<sup>23, 30</sup> Conflating fa'afafine and gender variant individuals with samples of other social groups in analysis without strong reasons to do so would cause selection error. However, it is still common to include individuals grouped by gender as an added sub-group to research with groups defined by sexual identity.<sup>28</sup> This produces results that confuse or conflate the experience of gender variant individuals with that of other groups. This practice also disregards diversity within gender variant sub-groups.

Many studies do not consider or compare differences between gender subgroups. For example, in the U.S., there is a lack of information about transgender men or women who identify themselves as men based on gender constructions.<sup>23</sup> Similarly, in Samoan culture, gender variant females are less socially visible than fa'afafine. Additionally, the experiences of fa'afafine individuals vary widely, depending on whether they live in urban or rural areas.<sup>7</sup> Therefore, in addition to analyses focusing on specific gender variant groups, researchers should also examine the dynamics of race, location, religion, class,

sexuality, disability and age within the fa'afafine and other gender variant communities so that the analyses capture this wide diversity and its socio-political contexts.<sup>28,30</sup>

## 2. Structure Gender Variables to Account for Gender Variance

Research on fa'afafine or gender variant communities should seek to make these communities institutionally visible. Instruments and databases should include methods of recording alternative gender variables, for they would be useful in contexts like Samoa. In order for policy makers and institutions to be aware of gender variant community needs, there needs to be data to support policy, funding and outreach. New Zealand's health statistics system recently published a conceptual framework on collecting data on sexual orientation, citing the sexual and gender diversity of the Polynesian immigrant population as an impetus. Though the framework focuses on designing ways to record sexual orientation variables, the authors also recognize the need for research on structuring gender variables for culturally diverse populations. Gender variables often frame the way sexuality is understood and needs to be considered in designing survey instruments.<sup>31</sup> Working with Polynesian gender variant communities, the authors found that respondents report their sexual orientation in relation to their gender identity (not biological sex), but would report to health officials based on their biological sex in a medical context.<sup>31</sup> Therefore researchers would have to ask questions differently and understand how third gender individuals would respond depending on the context research is being conducted.

Structuring gender variables is essential for research with gender variant communities. Answer options to survey questions could include man, woman, a culturally specific word for a gender variant category, "other" (to capture any gender category not considered) and a "Please describe your answer" option for respondents to elaborate on their choice. A separate question should record biological sex to control for instances where a gender variant may list themselves as a gender category that is not associated with their biological sex. Culturally specific understandings of gender categories should structure analysis. This would allow data to be captured and tracked for vulnerable sub-populations and make these sub-populations institutionally visible to service providers and allow for more effective outreach and care planning.

## 3. Community Guided and Community Serving Research

In addition to structuring methodology to provide better data on fa'afafine and gender variant communities, research should be directed by community needs and applied to address those issues. Previous research with the fa'afafine community has frequently been ethnocentric in design and has not produced data that health professionals can apply to serve the community. This leaves many questions about fa'afafine health status and their experience of health issues that may affect them in similar ways that have been documented in other third gender groups. As opposed to researchers dictating the agenda, fa'afafine life experiences and concerns should directly and explicitly inform research goals, hypotheses and methods, which would make the research more relevant to the participating community.<sup>27,28</sup> This would ensure research serves to utilize data, to solve problems in gender variant communities, or to mobilize activism.<sup>27</sup> Theorizing and constructing etiologies, as done by previous studies with fa'afafine, does not adequately address inequality or health disparities. Feminist health research and transgender/gender-variant affirmative research should be applied sciences, seeking to address marginalization through investigating the communities' health and social issues.<sup>27</sup>

## 4. Historical Consideration of Marginalization Experience

It has been suggested that considering ecological (social, histor-

ical and political contexts) factors surrounding gender variant health issues is important for working with gender variant communities globally.<sup>22</sup> For fa'afafine, understanding Samoa's colonization and Christianization is integral for understanding current conflicted social acceptance. Sexual and gender norms have changed greatly since Samoa's colonization. Fa'afafine are caught between traditional values and new values brought with globalization. Understanding this conflicted social acceptance can help providers understand the social contexts of fa'afafine health outcomes and help the providers navigate cultural attitudes in health service delivery. In addition, research should elucidate and discuss historical and present experiences of gender variant individuals and relations to institutions that affect their health and human rights.<sup>27</sup> Projects should account for how governments/institutions have previously worked with fa'afafine (and other gender variant groups). This would address any community distrust of research efforts and would advance social justice goals. Addressing histories of marginalization will improve how we interpret data about these communities.

## 5. Include Gender Variance in the Scope of Women's Health Research & Practice

When research is mobilized and applied to intervention programs, professionals should recognize that transgender, third gender, gender variant health issues are interconnected with women's health issues. For fa'afafine clients, maternal and child health programs need to take into consideration that motherhood in Samoan culture is not based on female biology. Clinics and programs need to be prepared for serving women with male anatomy or men with female anatomy in a women's health setting. Given the author's observations in American

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Samoa, this article argues that the inclusion of third gender women in women's health practice would be useful for health initiatives in other cultures. Women's health initiatives should be prepared to serve gender variant communities and address their marginalization in any country.

## Conclusion

Previous research with fa'afafine has been primarily focused on behavior etiology and is ethnocentric in design. This has left an absence of data about fa'afafine social and health needs, which service providers need to serve this community. The lack of data is also found in research of other transgender, third gender or gender variant groups globally. The absence of social and health needs data reinforces the social marginalization of fa'afafine and other gender variant groups, as providers lack information for intervention. This poses a challenge to public health and prevention efforts. Obtaining this information is a clear next step to better serving transgender, third gender and gender variant groups.

Study of fa'afafine provides an opportunity to restructure global health models of research, service delivery and outreach to incorporate third gender, gender variant and transgender communities. A fundamental assumption of Western women's health is that gender is a binary, and that women are defined in a population by biology. This assumption is challenged when gender binary models are confronted with different cultural contexts. In Samoan culture, fa'afafine demonstrate that motherhood and female social roles are not fixed to a female biology. Therefore, women's health needs to incorporate third gender communities in order to serve the health of all women, mothers and families as defined by the local culture. This is especially important as fa'afafine face marginalization, stemming from the same cultural misogyny biological women face. Marginalization and social vulnerability are compounded by the fact that health institutions and health research use gender binary models, obscuring what health experiences and outcomes are unique to fa'afafine. By understanding local categories of gender, public health efforts can maximize their cultural competency and reach historically underserved communities.

For the fa'afafine community, there is a need for research that measures the impact of health issues and directions for public health involvement in the following: (1) recording third gender status in health systems data, (2) addressing violence, (3) HIV and (4) maternal and child health issues. Sugges-

tions for conducting this research include (1) structuring research to capture diversity of fa'afafine and gender variant sub-groups, (2) structuring gender variables that adequately record third gender identities, (3) tailoring research to community needs to ultimately serve health improvement, (4) addressing historical experiences of social marginalization and (5) recognizing gender variant or third gender groups as integral to women's health initiatives. This can help providers and researchers strategize and best serve fa'afafine, third gender, transgender or gender variant people. With better data on health needs and better third gender research methods, public health providers and researchers can confront the challenge of incorporating fa'afafine (and other gender variant people globally) into a health and medical system that has been developed for a Western gender binary society.

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# Field Notes

## Combating Violence Against Anti-Polio Campaigns In Pakistan

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**Poliomyelitis has reemerged as a major global public health problem after being on the brink of eradication. Pakistan, especially its northwestern region, has been identified as the biggest hub of this resurgence. Here, the fight against polio has borne the brunt of the ongoing conflict between the State and the Taliban insurgents. At least 76 polio workers have been killed by the Taliban in order to frustrate anti-polio efforts. As the insurgents have broader militant objectives behind their actions, the Pakistani state should devise an urgent and comprehensive strategy to stop the polio spread. A two-pronged approach can be applied to address this problem. In conflict-prone areas, grassroots level awareness campaigns should be conducted to educate the people about the benefits of the polio vaccine. Meanwhile, in the rest of Pakistan, anti-polio vaccination efforts should be intensified for herd immunity. Additionally, the maximum level of security possible against potential insurgent attacks should be provided for the field vaccination teams.**

### Background

Polio is a virus that was responsible for the death and disability of hundreds of thousands of children every year during the first half of the twentieth century.<sup>1</sup> The discovery of an effective vaccine in 1955 and the launching of the Global Polio Eradication Initiative (GPEI) by the World Health Organization (WHO) and allied agencies in 1988 resulted in a 99% reduction in polio cases globally.<sup>2</sup> The annual number of cases dropped from the peak pre-vaccine rate of 600,000 to a few hundred by 2003.<sup>3,4</sup> Since there is no treatment available, the global strategy to eradicate poliovirus has been to vaccinate every child, causing the observed reduction in cases.<sup>5</sup> However, unexpected waves of polio resurgence have occurred over the last 8 to 10 years in a few Muslim-majority states, namely, Pakistan, Afghanistan, Nigeria and most recently, Syria (Figure 1).<sup>5,6,7</sup> One key factor in the recent spread of this disease is opposition from some religious figures who declared the vaccine haram (forbidden in Islam) over the rumors that it contains pork or could lead to sterility or HIV/AIDS.<sup>8,9</sup> The World Health Organization, considering this spread alarming, declared a “public health emergency of international concern” on May 5, 2014, and increased its efforts to stop further polio spread.<sup>7</sup> This was only the second time that the WHO had announced such an emergency since 2007, when the provision to do so was adopted into its regulations.<sup>10</sup> Due to the ability of poliovirus to spread swiftly and silently over large distances, the WHO had earlier warned that “failure to eradicate polio from these last remaining strongholds could result in as many as 200,000 new cases every year, within ten years, all over the world.”<sup>22</sup> Practically, this would mean the negation of much of the progress made in recent several decades. In addition to the looming threat of a worldwide return, the mere presence of even a few polio cases necessitates that expensive polio vaccination campaigns continue all around the world. According to GPEI, “polio anywhere is a threat to children everywhere.”<sup>11</sup> Economic models estimate a savings between \$40 and \$50 billion over the 20 years following potential polio eradication that would otherwise be spent on vaccination campaigns and treatment of

polio cases.<sup>12</sup>

Pakistan is presently identified as the largest reservoir and exporter of poliovirus; 306 of the total 359 world polio cases in 2014 and 20 out of the total 21 cases in 2015 (as of April) were from Pakistan.<sup>6</sup> Additionally, Pakistani strains of polio have been detected in Syria, Afghanistan and even Israel.<sup>10,13</sup> The country has traditionally struggled with a number of public health challenges in its fight against polio, including an inefficient health system, poor sanitary conditions, high prevalence of enteric infections and difficulty in maintaining a cold chain in remote areas.<sup>15</sup> Nevertheless, the country was previously successful in achieving its goals consistently over two decades preceding



**Figure 1. Federally Administered Tribal Areas (FATA) in northwest Pakistan.<sup>27</sup>**

2005—the year when the total number of positive cases had been reduced to only 28. Yet despite added measures by Pakistani authorities, polio is on the rise again.<sup>6</sup> A growing opposition by religious leaders in the recent past followed by an armed campaign against polio workers by the Taliban has jeopardized the polio vaccination program in many parts of the country, especially in the northwest tribal belt.<sup>14,15</sup> Millions of children are now left unvaccinated, resulting in the reappearance of the disease in many areas that were previously cleared of polio.<sup>16</sup>

This article will first review the most likely reasons behind the Taliban's violent campaign against polio workers in Pakistan and then give a detailed discussion of the existing and possible future measures to combat polio in the wake of this continued violence.

### Violence against Polio Workers: Taliban Strategy

Polio workers have been repeatedly targeted over the last few years all across Pakistan and are altogether banned in several areas in the northwest tribal belt neighboring Afghanistan (Figure 1).<sup>16</sup> Seventy-six polio workers and security escorts have been killed since June 2012 in different shooting incidents and thousands of others have been harassed in order to frustrate anti-polio efforts in the country. Various Taliban organizations have claimed responsibility for these killings.<sup>17</sup>

The most likely explanation for the Taliban campaign against polio workers is the world's attention to this disease.<sup>7,15,18</sup> Polio is near eradication and its completion would be one of the biggest humanitarian achievements after the smallpox eradication in the 1970s. The Taliban may hope that choking back anti-polio efforts at this stage will help them garner international attention. Additionally, the Taliban may see this campaign as an opportunity to gain leverage over the US and Pakistan. Their actions may be explained by their desire for the release of imprisoned Taliban fighters, the cessation of Pakistani military operations, and the end of US drone strikes.<sup>19</sup> One explanation for Taliban retaliation is evident in the 2011 incident where the CIA used a fake Hepatitis-B campaign to confirm the presence of Osama Bin Laden in a remote town.<sup>8,19</sup> As the details surfaced, the anger of Bin Laden's followers fell on polio workers, several of whom were killed in the following years.

A factor that might have helped the Taliban in their militant stance against polio eradication is the general stigma toward vaccination endemic in rural communities in remote Pakistan.<sup>20,21</sup> Here, vaccines are usually seen as an artifact of the western world and values. As a consequence, they are slow to be adopted by certain communities even outside areas with more extreme Taliban control. Conspiracy theories that the vaccine can cause HIV/AIDS or infertility are largely accepted as truth.<sup>21,22</sup> These sentiments only bolster the cause of the militants.

In summary, polio campaigns have suffered drastically due to the wider conflict between the state and the Taliban. The disease has practically become a political pawn at the hands of insurgents who had been in desperate need of a soft target. These militant actions are further supported by the genuine suspicion against vaccines held by the local populations.

### Combating Violence

The WHO, while declaring the state of emergency in May 2014, also imposed travel restrictions on Pakistan, mandating a polio vaccination certificate be produced before any international travel from the country.<sup>8</sup> This ban, along with the overall image of the country as being the biggest exporter of the virus, has exerted an enormous pressure on the Pakistani government. The state has taken extraordinary steps to bring the eradication efforts back in line, including coercive methods to vaccinate the children of populations generally wary of vaccination. In March 2015, more than 500 parents were arrested in the suburbs of the northwestern city of Peshawar for refusing to vaccinate their children.<sup>23</sup> They were later released after signing promises not to do so again. Similarly, police have been used in other parts of Pakistan to enforce compliance. Mini-curfews for a few hours have also been suggested and even implemented in some sensitive areas.<sup>24,25</sup> Certain civil society organizations have also stepped forward in providing assistance to polio campaigns. Karachi Rotary Club established voluntary vaccination centers at the transit points leading to so called “no-go areas” as well as at the toll plazas entering the city and public places such as railway stations.<sup>19,25</sup> More than a thousand local workers have been hired to educate people about the benefits of vaccination and to counter

rumors against such programs in visiting schools and mosques.<sup>19</sup> The state has also doubled the salary of vaccinators in peaceful areas and even more for those working in restive parts of the country.<sup>19</sup> Public health workers provide vaccines to the children in the government-managed temporary camps for the populations displaced due to the military operations. Some religious clerics have also been courted to support the vaccination programs and issue Fatwas, Islamic decrees, to declare vaccine ‘halal’

(allowed in Islam).<sup>24</sup> These measures in conflict-prone areas have the potential to change the anti-vaccine sentiment prevalent among their populations.

### Discussion

The worldwide war on polio is far from over. Its final stages have been met with some of the most difficult geopolitical circumstances in recent history. With a new, deadly political force now protecting and facilitating the spread of this ruthless disease, the anti-polio camps also need to devise and follow a carefully delineated national strategy if there is to be any hope for success.

From the perspective of polio eradication efforts, two disparate regions of Pakistan can be identified: (1) the conflict prone northwestern tribal belt, also known as the Federally Administered Tribal Areas and (2) the remaining relatively peaceful Pakistan. Therefore, it is recommended that the vaccination efforts be tailored to suit the situation of these individual areas as suggested below.

The northwest tribal region comprises only 2% of the total Pakistani population.<sup>25</sup> However, the magnitude of problems here demands a disproportionately larger allocation of resources. Many areas in this tribal belt are under the direct influence of the Taliban. In the near future, they may gain further strength due to their growing influence in neighboring Afghanistan as NATO forces withdraw.

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**Most of the rest of the  
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Therefore, any strategy to combat violence against polio campaigns requires developing trust and understanding at the grassroots level through direct community engagement rather than only negotiating with the militant leaders. Awareness about the importance of vaccination for individuals and for humanity as a whole should be disseminated through culturally sensitive approaches through local outlets and people, namely healthcare workers, teachers and the media. There are reports of the positive impact of such measures in the past; parents have defied the Taliban to get their children vaccinated by secretly bringing vaccines home or by taking their children to the local medical centers when vaccination teams cannot reach them.<sup>26</sup> Some non-Taliban religious leaders have supported the polio campaigns in the past. Efforts should be made to convince more members of the religious clergy to join this humanitarian cause, since they hold substantial influence on local populations.

On the other hand, most of the rest of the Pakistani population has historically been compliant to the vaccination programs; 84% of them agree on the benefits of vaccines.<sup>20</sup> However, attacks by the Taliban on polio teams in the field have left a large cluster of populations unvaccinated even in these peaceful areas. Therefore, a different, aggressive approach, in which intensified vaccination campaigns are organized under the principle of herd immunity, may be effective here. To further motivate people and to ensure complete coverage, awareness should be raised through electronic and print media, informational banners, billboards and motivational media statements by prominent figures. Moreover, completed vaccination cards should be required for admissions to schools. Further, stricter actions such as local holidays and even local curfews in the sensitive areas during vaccination times should be implemented more frequently. These anti-polio measures should be accompanied by heightened security measures to thwart possible attacks by Taliban assailants.

In reality, different parts of the area may need a different mix of these approaches because of regional diversity in beliefs, awareness levels and security situations. In areas with sparse governmental control and distrustful or hostile populations, the general opinion should first be changed through systematic yet measured re-education. This would likely be a slow process, but it may be the only way forward in certain situations. The results, once achieved, would be perpetuated farther and for longer periods of time.

Conversely, in areas with relatively high education and awareness, the more vigorous, open approaches described above should be the main focus.

Similarly, at the national level, a comprehensive strategy should be devised, with some flexibility put in the hands of the local administration. Categorical evaluation of the successes and failures at the local levels will be an invaluable tool for future planning. Media and other awareness campaigns should be used to start an organic, urgent dialogue on the topic and to convince more of the population of the need for vaccination.

Finally, international deadlines should not be implemented because they can put undue pressure on local authorities, causing them to prematurely switch to intense approaches where a steady hand is needed, as has been observed. It is worth noting that all of these steps may produce results that may at first seem to fall short of expectations; however, the key to success lies in flexibility and switching between methodologies in case one fails so as to ensure consistent, if not rapid, progress.

## Conclusion

Politicizing the task of eradicating polio, to the extent that of inciting bloodshed, is unacceptable. In spite of this bloodshed, it is clear that the world cannot afford to stop so close to complete eradication. The combined resolve of all those concerned and affected is the most powerful weapon in winning this struggle. There are a number of approaches to be considered, each effective on its own scale. Choosing the approach based on the particular demographic and social context of each region is the key to long-term, self-perpetuated success. It is necessary to learn from past attempts to eradicate polio in different regions of Pakistan in order to move toward to the goal of total eradication.

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