

# A Pilot Study for Health Promotion and Protection of Infants with Tongue-tie Related HIV: Healthy Mums and Babies Program

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## ABSTRACT

Infants in rural and remote populations were presented with positive Human Immunodeficiency Virus (HIV) status when parents were healthy (HIV negative). This was a serious concern to clinicians as to how a newborn baby (within 12 months of birth) could be HIV positive when the parents were HIV negative. The infants had no history of any blood transfusion or surgery. With evolving pathogenesis, viral mutagenesis patterns and spreading mediums of viral diseases, this is a serious question to be addressed. Clinicians treating these infants suspect that this is a case of HIV viral mutagenesis. Assumptions about the cause of tongue ties (ankyloglossia) and its effect on families are prevalent in some rural sub-populations. These underlying

myths could lead parent(s) to take their infants to surgical treatment (frenectomy) by unlicensed and untrained persons, sometimes referred to as “quack doctors”. The individuals who perform these frenectomies often use unsterilized surgical instruments that have been contaminated in use with HIV positive patients. As a result, there is a need to conduct a need analysis in rural populations to assess the infant HIV magnitude, including the prevalence and incidence rates of HIV in infants. This research project primarily focuses on finding and contrasting the proportion of HIV positive to HIV negative infants with tongue ties. This project also aims to evaluate the perception and knowledge of tongue ties by mothers or caregivers leading them to seek treatment with unlicensed persons, assessing the impacts of tongue ties

on infant breastfeeding and speech. Moreover, to determine treatment needs required on infants with underlying oral health problems due to tongue tie.

**Key Words:** Tongue-tie, Infant HIV, Health Promotion, Needs Analysis, Ankyloglossia, Health Protection

## BACKGROUND

Human Immunodeficiency Virus (HIV)/AIDS pandemic related morbidity and mortality rate is a global public health issue. [1-4] This public health issue could be effectively addressed by focusing on the mortality and morbidity rates of infants of the HIV pandemic population. [5,6] Infants from rural and remote populations who attended as patients at the Levy Mwanawasa University Teaching Hospital were presented with positive Human Immunodeficiency Virus (HIV) status when their parents were healthy (HIV negative status).

These infants had no history of exposure to risk factors like blood transfusion, contact to body fluids or surgery. This was a serious concern to clinicians as to how a newborn baby (within 12 months of birth) could be HIV positive when the parents were HIV negative. With evolving and changing pathogenesis, viral mutagenesis patterns and spreading mediums of viral diseases, this was a serious question to be addressed in the case of HIV virus. [7-9]

Clinicians like doctors, dentists, nurses etc. treating these infants were concerned if they were unravelling the tip of an iceberg with a possible HIV viral mutagenesis. [9] Assumption and myths in some rural population about HIV/ AIDS is a barrier in reducing the incidence and transmission rates of HIV. [10-13] Assumptions and myths about the cause of tongue tie (ankyloglossia) and its effect on families are prevalent in some of the rural sub-population. These underlying assumptions and myths possibly made the parent/s to take their babies to surgical treatment (frenectomy) by unlicensed and untrained persons, sometime

referred to as “quack doctors”. [14-16] These “quack doctors” often use unsterilized surgical instruments in infants which they used on HIV positive patients too. Most of these places which reported HIV positive infants due to treatment by quack doctors have well established government hospitals or rural clinics with highly skilled clinicians (doctors, dentists, nurses, health workers etc.). So now the question arises on why the patients are still going to a person with no professional training for treatment and how many infants who had frenectomy with “quack doctors” have been infected with HIV.

Ankyloglossia, more commonly called “tongue-tie” is a congenital anomaly characterized by an abnormally short and thick lingual frenum, which may restrict tongue tip mobility [17] Lingual frenulum is a membrane that connects the tongue to the floor of the mouth and influences the growth and development of the oral and maxillofacial cavity affecting breathing, occlusion, suction, swallowing and speech. [18,19] Lingual frenulum is an embryonic residual tissue that originates in the stages of development of the oral cavity, and sometimes an incorrect division of the genioglossus and hyoglossus muscles, leaving the frenulum outside the tongue. [20-22] Incidence rates of ankyloglossia reported in the literature vary widely, ranging from 0.02% to 10.7%. [23] The incidence among outpatients of a children’s hospital with breast-feeding problems was almost three times higher. Oral anomalies in neonates found a significant three times predilection for Ankyloglossia in males. [24] A surgical procedure called frenectomy is used to cut the restricting binding tissue to the tongue as a surgical intervention for tongue-tie in infants. [25]

## Principal Objective of the study

To determine the incidence of tongue tie related HIV in the babies born at Levy Mwanawasa University Teaching Hospital with (LMUTH) to healthy infants.

### Specific Objectives

- To determine the proportion of babies born with tongue tie.
- To evaluate the perception of tongue tie by the mothers and care givers and why they are doing frenectomy with an unlicensed and untrained person.
- To evaluate the knowledge that the mothers and care givers have on tongue tie.
- To assess the associated effects on breastfeeding and speech in infants with tongue ties on.
- To determine the treatment needs required on babies with undelaying oral health problems due to tongue tie.

## METHODOLOGY

### Study design

A hospital based cross sectional study is to be conducted at Levy Mwanawasa University Teaching Hospital.

### Study Population

The target population will consist of babies born at Levy Mwanawasa University Teaching Hospital aged less than one year old who was born with tongue tie and those without. Infants born with tongue tie are placed on a special focus to determine HIV status. The age limit was arrived at to enable the study to capture the babies who will be brought for post-natal care (immunization).

### Participants selection

The following the inclusion and exclusion criteria will be observed during the participant recruitment process: Inclusion criteria include Babies young than 6 months, babies who are presenting in good health state and babies born from levy Mwanawasa teaching hospital and attending post-natal care. Exclusion criteria include Mothers/caregivers who will not provide full and valid consent, babies above 6 months and babies with a diagnosis of a systemic disease or syndrome.

### Sampling procedure

Simple random sampling will be used in this study since the participants to be investigated will be the ones accessing the post-natal services Levy Mwanawasa University Teaching Hospital.

### Sample size

The sample size will be determined by using Yamane's formula by assuming that 50% of the patients will have a tongue tie to obtain maximum sample size with 95% confidence level and 5% level of significance (Yamane,1967). Thus, with the formula,  $sample\ size\ (n) = \frac{N}{1+Ne^2}$ , the estimated sample size is 308.

### Data Collection

This research will obtain information through:

1. Extraction of data from the babies under five cards,
2. An oral health questionnaire, as conducted by a face-to-face interview with each mother or caregiver using a structured questionnaire between 5 -15 minutes, and
3. A brief intra-oral examination of the babies that obtained clinical data for the presence or absence of tongue tie. Dental examinations are to be carried out in children who are going to participate in the study. The examiner is going to use wooden spatula and natural light and sit in front of the children. Before the dental examination, parents are going to be given questionnaires. The questionnaire will be prepared in English. (1) Socio-demographic variables: age, sex, occupation, marital status, educational level. (2) General knowledge on tongue ties, treatment needed, treatment done if any. A research instrument has been designed to record the clinical findings.

## STATISTICAL ANALYSIS

The questionnaire answers obtained from the participants will undergo coding in the excel sheet. The collected data will be

analysed using Statistical Package for Social Sciences version 16.0. Descriptive statistics will be used to summarize numeric and qualitative data to generate frequencies, measures of central tendency and measure of spread. Tables and graphing techniques such as bar graphs will be used to present data.

## RESULTS

The results found from this study will be used to design and implement a possible national health promotion program focusing on HIV prevention for infants.

## DISCUSSION

Mothers who reported having a baby with tongue tie, the diagnoses made by themselves.<sup>[26]</sup> The diagnosis of tongue tie should be done by adequately trained personnel to limit unnecessary interventions.<sup>[26,27]</sup> These points towards the need of an education program for mums. Clinical literature and definitions have some degree of variance when identifying ankyloglossia. Tongue-tie or ankyloglossia is described as a congenital condition with an unusually thickened, tightened or shortened frenulum (membrane under the tongue).<sup>[28]</sup>

The term “ankyloglossia” was first used in the medical literature as back as the 1960s. At that time, tongue-tie was described as a condition in which the tip of the tongue cannot be protruded beyond the lower incisor teeth because of short frenulum linguae, often containing scar tissue.<sup>[28]</sup> Later this definition evolved to become more precise with supporting incidence rates. Tongue-tie was later defined as a congenital or hereditary oral anomaly that occurs in between 2.8% to 10.7% of all infants.<sup>[29-32]</sup> These findings collate to the prevalence of 4.2–10.7% found in a 2007 review by Segal et al.<sup>[23]</sup> Another study reported that tongue-tie occurs in male infants than female infants and a higher incidence in infants compared to adult population. This age-related difference is attributed to fact there is possibility of

resolution of mild of tongue tie with growth.<sup>[22]</sup>

Clinically acceptable, normal range of free tongue movement is greater than 16 mm.<sup>[33, 34]</sup> The ankyloglossia can be classified into 4 classes based on Kotlow's assessment as<sup>[33, 34]</sup> Class I: Mild ankyloglossia: 12 to 16 mm, Class II: Moderate ankyloglossia: 8 to 11 mm, Class III: Severe ankyloglossia: 3 to 7 mm and Class IV: Complete ankyloglossia: <3 mm

Correct and timely diagnosis of ankyloglossia (tongue tie) is not only critical to physical health but also to future emotional health of an infant. Dental caries could occur due to food debris not being removed by the tongue action of sweeping the teeth and spreading of saliva. Malocclusion like open bite due to thrust created by being tongue tied, spreading of lower incisors with periodontitis, and tooth mobility due to long-term tongue thrust are associated problems. It also affects self-esteem because it has been clinically noted that occasionally older children or adults will be self-conscious or embarrassed about their tongue-tie because they may have been teased by their classmates for their anomaly.<sup>[31]</sup>

## CONCLUSION

There has been no formal study in Zambia on the incidence and prevalence on Ankyloglossia (Tongue tie) in the population and the myths associated with the condition, in the population. Oral health and quality oral health care add to holistic health, which should be a right rather than a privilege to individuals despite their status in life. That is why individuals with disabilities such as tongue tie deserve the same opportunities for dental services as those who are healthy. A number of parents and guardians in the community are presenting at the University Hospital with babies having tongue-tie and revealing myths/ misconceptions, when communicating about the condition. The problem is we do not have formal base-line data about how big is the problem in the



target population (prevalence rate) and how bigger it is getting (incidence rate) and current knowledge of the parents and guardians about tongue-tie. This gap in available information (data) on the tongue-tie condition in the target population and parent/guardian knowledge has been never addressed. This research could shed light into normative needs of the community related to tongue-tie condition than still depending on self-reports from community and develop a harm reduction community program. This clinically assessed data would be more accurate and valid in determining the clinical treatment needs in the community. Therefore, the outcome of this study will outline the baseline data on the incidence, relevance and treatment needs among babies born with tongue tie related HIV and just tongue -tie at Levy Mwanawasa University Teaching Hospital. This data would help policy makers immensely in planning for health promotion programs and health protection programs with infant population, both provincially and nationally.

#### **Declaration by Authors**

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