THE CHARACTERISTICS OF CHILDREN AGED ONE MONTH TO 14 YEARS WITH TUBERCULOSIS IN PUBLIC HEALTH FACIITIES IN JUBA CITY, SOUTH SUDAN

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DECLARATION

I, Linda Levi Enoka, declare that this study is my own original work and has not been presented to any university or institution of higher learning.

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DEDICATION

I wish to dedicate this book to my late son Nathan Lemmy whose memory keeps me going on and to my husband Steven Lemmy who had been a great support throughout my study. Finally, to all the children suffering from tuberculosis; may God spread his healing hands upon them.

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LIST OF ABBREVIATIONS

AAFB	:	Alcohol and Acid fast bacilli
AIDS	:	Acquired Immune Deficiency Syndrome
ARD	:	Acute Respiratory Disease
BCG	:	Bacillus Calmette-Guerin
CAU	:	Census Area Unit
CDC	:	Centre For Disease Control
CPA	:	Comprehensive Peace Agreement
FDGs	:	Focus Group Discussions
HIV	:	Human Immunodeficiency Virus
IDP	:	Internally Displaced Person
LTBI	:	Latent tuberculosis infection
MDGs	:	Millennium Development Goals
NTLBCP/GOSS	:	National Tuberculosis, Leprosy and Buruli ulcer Control Programme, Government of South Sudan.
PHC	:	Primary Health Care
PHCC	:	Primary Health Care Centre.
SES	:	Socioeconomic status
SPLM	:	Sudan People's Liberation Movement
SPLA	:	Sudan People's Liberation Army
SPSS	:	Statistical Package for Social Sciences
TB	:	Tuberculosis
TST	:	Tuberculin Skin Test
UNDP	:	United Nations Development Program
USAID	:	United States Agency For International Development
WHO	:	World Health Organization

DEFINITION OF TERMS

AIDS	:	Is a disease of the human immune system caused by the human immunodeficiency virus (HIV). This condition progressively reduces the effectiveness of the immune system and leaves individuals susceptible to opportunistic infections and tumours. HIV is transmitted through direct contact of a mucous membrane or the bloodstream with a bodily fluid containing HIV, such as blood, semen, vaginal fluid, pre-seminal fluid, and breast milk.
BCG	:	A vaccine prepared from an attenuated strain of the tubercle bacillus, used for immunization against tuberculosis. Origin: b(acillus) C(almette-)G(uérin), after A. L. C. Calmette (1863-1933) & Camille Guérin (1872-1961), For physicians who developed it
HIV	:	HIV (human immunodeficiency virus) is the virus that causes AIDS. This virus is passed from one person to another through blood-to-blood and sexual contact. In addition, infected pregnant women can pass HIV to their baby during pregnancy or delivery, as well as through breast-feeding. People with HIV have what is called HIV infection. Most of these people will develop AIDS as a result of their HIV infection.
LTBI	:	Is where a patient is infected with Mycobacterium tuberculosis, but does not have active tuberculosis disease. Patients with latent tuberculosis are not infectious, and it is not possible to get TB from someone with latent tuberculosis.
Lymph node	:	Is a small ball-shaped organ of the immune system, distributed widely through the body including the armpit, stomach/gut and linked by lymphatic vessels.
Lymph-adenopathy	:	Is a term meaning disease of the lymph nodes. It is, however, almost synonymously used with swollen/enlarged lymph nodes. It could be due to infection, auto-immune disease, or

malignancy.

MDGs	:	Are eight international development goals that all 192 United Nations member states and at least 23 international organizations have agreed to achieve by the year 2015. They include eradicating extreme poverty, reducing child mortality rates, fighting disease epidemics such as AIDS, and developing a global partnership for development.
Miliary tuberculosis		Is the widespread dissemination of Mycobacterium tuberculosis via hematogenous spread. Classic miliary TB is defined as milletlike (mean, 2 mm; range, 1-5 mm) seeding of TB bacilli in the lung, as evidenced on chest radiography. This pattern is seen in 1%-3% of all TB cases.
PHC	:	Is essential health care based on practical, scientifically sound and socially acceptable methods and technology that are universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self determination.
SES	:	Is an economic and sociological combined total measure of a person's work experience and of an individual's or family's economic and social position relative to others, based on income, education, and occupation.
SPLA	:	Is a rebel group that was formed in 1983. It has since fought against the governments of Gaafar Nimeiry, Sadiq al-Mahdi and President Omar Hasan Ahmad al-Bashir. Its leader, the late Dr. John Garang, a Dinka, holds a doctorate and received military training in the USA. The SPLA is the military wing of the SPLM, the Sudan People's Liberation Movement. The SPLA is largely southern-based, non-Arabic and non-Muslim, in contrast to the predominantly Muslim and Arab north. Their declared aim was to establish a secular and democratic Sudan. While the war in South Sudan had been largely described in religious and ethnic terms, it is also a struggle for control of

		the oil resources located in the south.
TB	:	An infectious disease of humans and animals caused by the tubercle bacillus and characterized by the formation of tubercles on the lungs and other tissues of the body, often developing long after the initial infection. Tuberculosis of the lungs, characterized by the coughing up of mucus and sputum, fever, weight loss, and chest pain.
TST		The tuberculosis skin test (also known as the tuberculin test or PPD test) is a test used to determine if someone has developed an immune response to the bacterium that causes tuberculosis (TB). This response can occur if someone currently has TB, if they were exposed to it in the past, or if they received the BCG vaccine against TB (which is not performed in the U.S.). The World Health Organization estimates that 2 billion people worldwide have latent TB, while around 3 million people worldwide die of TB each year.
Tuberculous meningitis		Is Mycobacterium tuberculosis infection of the meninges—the system of membranes which envelops the central nervous system. It is the most common form of CNS tuberculosis

ABSTRACT

Introduction:

Tuberculosis is a specific, chronic, infectious, debilitating disease caused by infection with Mycobacterium tuberculosis characterised by night sweats, fever, weight loss, chronic cough, and chest pain.

The site for infection is mainly the lungs but any other body organ can be affected. The disease is mainly transmitted through inhalation of an infected droplet or aerosol from an infected individual when they cough, sneeze or talk and they pass the aerosol to the surrounding air, and a healthy person gets it by inhaling the infected air. The disease mainly affect the elderly, people with HIV/AIDS, those on medication which lowers their immunity, those living in overcrowded conditions, young malnourished children and any persons living under conditions which compromise their immune system.

Tuberculosis (TB) is a public health problem in South Sudan contributing to 228 cases per 100,000 populations. There were 1,652 deaths every year for every 100,000 people. This increase in cases was as a result of the prolonged civil war of which the children could mostly be affected in light of the high number of cases in adults. Cross-sectional study on the characteristics of children under the age of 15 years with tuberculosis was therefore an important approach that will enable strengthen control programmes on tuberculosis with regard to childhood tuberculosis.

Purpose: The purpose of this study was to establish the characteristics of children under the age of 15 years with tuberculosis in public health facilities in Juba, South Sudan.

Study setting: Juba, tuberculosis clinics which were located at three areas which are Juba Teaching Hospital, Kator PHCC and Munuki PHCC.

Study design and Methodology: Hospital based cross-sectional study of children who met the inclusion criteria.

Study population: 1 month to 14 years children with diagnosis of TB using WHO diagnostic guide-line and meeting the inclusion criteria.

Data analysis: quantitative data were analysed using Epi Info 3.5.4 and qualitative data were analysed thematically.

Results: a total of 330 children aged between one month and fourteen years and their parents/caregivers took part in the study. On analysis, history of caregivers staying in an IDP camp gave an estimated RR of 1.59 with a 95% CI (1.27, 1.96) and a P-value of 0.00015 showing a significant association between staying in an IDP camp and history of tuberculosis in the family and occurrence of the disease in a child.

Conclusion: Staying in an IDP camp showed a significant association with tuberculosis occurrence in a child. The rest of the factors need to be tested in further studies to help the programmes to advocate for childhood tuberculosis to be integrated into existing programmes with intense focus.

Recommendations: mechanisms/guidelines should be put in place to screen and treat people staying in IDP camps or with a history of having stayed in an IDP camp for TB.

CHAPTER ONE

1.0 INTRODUCTION

Tuberculosis is a specific, chronic, infectious, debilitating disease caused by infection with Mycobacterium tuberculosis characterised by night sweats, fever, weight loss, chronic cough, and local pain. (medilexicon's medical, 2006 , the American heritage 2009, Collins 2003, English dictionaries). The site for infection is mainly the lungs but any other body organ can be affected. The disease is mainly transmitted through inhalation of an infected droplet or aerosol from an infected individual when they cough, sneeze or talk and they pass the aerosol to the surrounding air, and a well person gets it by breathing the infected air. There are rare routes of infection like the mucous membranes. Other species of mycobacterium also cause tuberculosis. The disease mainly affects the elderly, people with HIV/AIDS, those on medication which lower their immunity, those living in overcrowded conditions, young malnourished children and any persons living under conditions which compromise their immune system.

Children are at special risk for tuberculosis because their immune system is still developing. The children most at risk are malnourished children, those who are HIV/AIDS positive and those who stay with individuals positive for tuberculosis.

Characteristics of children with tuberculosis to be addressed in this study refer to their age, sex and Health facility they attended. The age and sex of the parents/caregivers, history of staying in an IDP camp, history of TB case in the household, history of more than four people sharing a room in the household and educational level of the parents/caregivers. And finally the knowledge of the parents/caregivers of the children with tuberculosis with regard to the agent that causes tuberculosis, the mode of transmission and the methods of prevention.

Tuberculosis (TB) is the most important prime infectious killer disease of children and adults in the developing countries. One third of the world's population is infected with Mycobacterium Tuberculosis, the causative organism of TB creating a huge burden from the disease (Rekha and Soumya 2007). In children TB has been ranked among the 10 major causes of mortality. Although TB continues to be an important cause of morbidity and mortality in children, the diagnostic difficulties, coupled with the lack of data on treatment outcomes and the dogma that childhood TB can be prevented by treating adult

infectious cases are major obstacles in estimating the true burden of TB disease in children.

According to World Health Organization, around 9.2 million new Tuberculosis cases were reported worldwide annually in 2006, including 709,000 cases among those with HIV/AIDS (WHO, 2008). Two million people die of Tuberculosis every year. Tuberculosis is the second cause of death due to infectious disease after HIV infection (Varaine, *et al* 2010).

Those children who live in a household where there is an infected person are at highest risk of developing tuberculosis (Zellweger, 2002). Children are not infectious because they don't have significant cough and even if they have, they don't produce sputum, and even if they produce sputum, the organisms are sparse in the bronchial secretions of children. Children also lack the tussive force necessary to suspend infectious particles of the correct size in the air (Stark, 2001).

This study aimed at establishing the characteristics of children aged 1 month to 14 years with tuberculosis in public health facilities in Juba, South Sudan.

1.1 Background:

Tuberculosis is a major cause of morbidity and mortality in South Sudan (USAID, 2009). The control of tuberculosis is limited and only 25% of the total population is covered (UNDP, 2010). The burden of TB in children in Southern Sudan is not known because no studies have been conducted in this age group to my knowledge.

According to WHO the incidence of all forms of tuberculosis in 2007 was 243 cases per 100,000 populations for the whole of the Sudan. The region of South Sudan alone accounts for 228 cases per 100,000 populations (USAID, 2009). Tuberculosis increased because of the long civil war in Sudan. The war gave rise to poverty, malnutrition and a large number of displaced populations and refugees. The health infrastructures were destroyed and health personnel were displaced. All the above factors led to the rise in tuberculosis cases in South Sudan (USAID, 2009). According to WHO, the incidences of all tuberculosis are 228 per 100,000 populations.

1.1.1 The cause of tuberculosis:

Tuberculosis is an infectious disease caused by organisms of the genus mycobacterium. Mycobacterium is long, about 2 to 4 micrometers in size and is an alcohol and acid fast bacillus (Batra and Jocelyn 2009). Those that are responsible for tuberculosis infections are termed as tuberculosis complex species and they include: Mycobacterium tuberculosis, Mycobacterium bovis, along with Mycobacterium africanum and Mycobacterium microti. Opportunist mycobacterium or environmental mycobacterium may also cause disease in humans. They are also called atypical or anonymous mycobacterium. These are found in the soil, dust and water. Some species are Mycobacterium phlei, Mycobacterium smegmatis, these two sometimes act as saprophytes. Other opportunistic Mycobacteria are Mycobacterium kansasii which can occasionally cause disease in humans. There is also Mycobacteria avium-intracellulare. These and others cause disease in homosexual men, intravenous drug users and those who develop immunodeficiencies. They occur in humans as normal flora. They may be found in the intestine, perineal skin and skin of the genitalia (Batra and Jocelyn 2009).

1.1.2 Transmission of tuberculosis:

Tuberculosis is an infectious disease which spreads through the air. A person who has pulmonary tuberculosis is infectious and can spread mycobacterium to healthy people when they cough, sneeze, talk or spit. Those who are well get infected through inhalation of the contaminated air (WHO, 2010; Varaine *et al*, 2010). The environment can be decontaminated by sunlight and ventilation (Varaine *et al*, 2010). Other means of infection are far less common, transmission could be cutaneous or through mucous inoculation of laboratory personnel or digestive contamination in case of bovine tuberculosis.

1.1.3 Treatment of tuberculosis:

Anti-tuberculous treatment is divided into two phases, intensive and continuation phase. The intensive phase is to quickly eliminate the majority of the organisms and to prevent emergence of drug resistance. In this phase, more drugs are used. The continuation phases use fewer drugs to eradicate the dormant organisms. Examples of these drugs are isoniazide (H), rifampicin (R), pyrazinamide (Z), ethambutol (E), and streptomycin (S) (WHO, 2006). The drugs used for treating children with tuberculosis in South Sudan are isoniazid, rifampicin, pyrazinamide and ethambutol.

1.1.4 Risk factors for tuberculosis in children:

Epidemiologically, risk factors for tuberculosis differ between developed and developing countries (Reheka and Soumya 2007). In developed countries, tuberculosis in children forms about 2.7 % of all TB cases and mainly is in immigrants (Rekeha and Soumya 2007).

Some of the risk factors are: adverse social circumstances like homelessness, mental illness or substance abuse in the family, a previous history of adherence in the family and poor adherence to the therapy or failure to attend the clinic for cases of tuberculosis (Corrigan and Paton 2007). The number of secondary TB cases in a given setting is determined by the family size, population density and median age of TB patients (Rekeha and Soumya 2007). Young age and HIV infection are associated with more disseminated disease and HIV infection increases severity by a factor of twenty (Rekeha and Soumya, 2007). Immune deficiency has been found to be caused mostly by HIV infection in most parts of the world including Sub-Saharan Africa. Those children who are HIV positive are at high risk of tuberculosis (Corrigan and Paton 2007). Poverty, overcrowding and malnutrition are some risk factors for tuberculosis in children.

1.1.5 Tuberculosis in children:

Tuberculosis is hard to diagnose in children since children can not produce sputum for microscopy. And in many of the developing countries the diagnoses use microscopy of the sputum. As a result, tuberculosis in children is difficult to diagnose giving rise to under-reporting and many children die without being diagnosed or treated (CDC, 2001).

1.1.6 Diagnosis for tuberculosis in children:

According to WHO guidelines, diagnosis of TB in children should be done as follows:

When a child is ill and has a history of contact with a tuberculosis patient suspect or confirmed case.

A child who doesn’t recover after an attack from measles or whooping cough.

A child with loss of weight, cough and fever and doesn’t respond to antibiotic therapy for acute respiratory disease.

Abdominal swelling, hard painless mass and free fluid (WHO, 2000).

1.1.7 Treatment of tuberculosis in children:

The treatment is similar to that in adults but differ as follows:

The dosages in children should be higher per kilogram body weight because they have a high metabolism; they tolerate higher doses with few side effects.
Children have fewer organisms and are less likely to develop secondary resistance.
Extra-pulmonary TB is more common in children and therefore the drugs used should be able to penetrate and achieve required concentrations in specific body fluids and tissues (WHO, 2009).

1.1.8 Prevention of tuberculosis in children:

Early diagnosis and treatment of an infectious adult is the best way to protect children from getting infected. BCG immunization of babies soon after birth up to two years of age will protect them against development of tuberculous meningitis (WHO, 2009). WHO 2009 report on tuberculosis set some targets for tuberculosis control and these are:

By 2015 TB incidence should decrease according to Millennium Development Goals MDGs no. 6.

The prevalence and death rates due to tuberculosis should be halved by 2015 compared to the rates in 1990. (WHO, 2006)

And seventy percent of smear positive cases should be detected and treated in the programmes.

At least 85% of the smear positive cases should be successfully treated.

1.1.9 Complications of tuberculosis in children:

Tubercular meningitis is one of the most severe complications of tuberculosis in children. It occurs in 5 to 10% of children younger than 2 years. The onset is usually 3 to 6 months after the initial infection. Symptoms are anorexia, weight loss and fever. Following two weeks, vomiting, seizures, mental deterioration, coma and death may result despite prompt diagnosis and early intervention. Tubercular meningitis is extra pulmonary tuberculosis. Other types include peripheral lymph-adenopathy, miliary tuberculosis, skeletal tuberculosis and other organ involvement. (Batra and Jocelyn, 2009).

1.1.10 Pathophysiology of tuberculosis:

In children, the port of entry is through the respiratory tract. Ingestion of milk contaminated with bovine tuberculosis can lead to gastrointestinal primary lesion. On rare

occasions, infection of the mucous membranes can occur through an abrasion, cut or insect bite (Stark, 2001). In case of a lung infection, the bacilli multiply first in the alveolar ducts. Some of the bacilli are ingested but not killed by the macrophages that carry the organisms through lymphatic channels to the regional lymph nodes. In children the major lymph nodes involved are the hilar lymph nodes, others are paratracheal and subcarinal nodes (Stansberry, 1990). Following inhalation, delayed hypersensitivity occurs usually between 3 and 12 weeks, mostly 4 to 8 weeks. Some children may experience some febrile illness that lasts 1 to 3 weeks when the hypersensitivity develops. There is mild cough and other respiratory symptoms (Stansberry, 1990). The primary complex of tuberculosis consists of local reactions in the parenchyma of the lungs where the organisms lodge and the inflammatory reaction of the associated lymph node (Morrison, 1973). The parenchyma portion of the primary complex heals completely by fibrosis and is of no clinical significance. Sometimes the lesion continues to enlarge resulting in focal pnuemonitis and thickening of the overlying pleura. The foci in the regional lymph nodes develop fibrosis but healing is not complete as in the parenchymal lesion. Mycobacterium tuberculosis may persist for decades after calcification or fibrosis of the lymph nodes (Lincoln *et al*, 1958).

For the first infection, the child develops a positive tuberculin test, the lymph node is normal in size. The parenchyma of the lung is not visible on the chest x-ray and the child has no symptoms and no complications. This stage is tuberculosis infection and most children have a normal chest radiograph. Sometimes the child will have an enlarged lymph node. Such nodes can encroach on the bronchus causing obstruction. Complete obstruction can cause atelectasis of the lung segment (Lincoln *et al,* 1958). The bacilli can also spread from the primary complex through the bloodstream and lymphatics to many parts of the body and commonly they get seeded in lung apices, liver, spleen, meninges, peritoneum, lymph nodes, pleura and bones. These can lead to extra-pulmonary tuberculosis. Around 0.5 to 2% of children develop massive lymphohematogenous dissemination leading to miliary or disseminated tuberculosis within three to nine months of acquiring infection (Stark, 2001).

1.2 Problem statement

At least 500,000 children contract tuberculosis each year, and 70,000 children die of the disease annually (WHO, 2012). Tuberculosis claimed 1.7 million lives in 2006, including 231,000 people living with HIV/AIDS, this equals 4,500 deaths per day (WHO, 2008). Tuberculosis is second to HIV as the leading cause of death due to infectious diseases. It also kills more women than other causes of maternal mortality combined. It is also the leading infectious killer of people with HIV (WHO, 2008).

Tuberculosis is a global issue. WHO estimates that two billion people are infected with Mycobacterium tuberculosis, about a third of the world population (WHO, 2008). Thirteen million people worldwide have active form of the disease at any one moment. Increase in drug resistant strains and synergy with HIV has threatened the control of tuberculosis. HIV and poverty has contributed to rising incidence of tuberculosis in many parts of the world where the epidemic is on the increase.

One third of the world's population has been infected with TB. New infections occur at the rate of one per second. In 2007 there were 9.3 million new cases and 1.8 million deaths. Annual incidence rate varied from 363 per 100,000 in Africa to 32,000 in the Americas. Resurgence in tuberculosis is due to the rise in HIV infections and neglect in Tuberculosis Control Programmes (WHO, 2008). Most of the disease in children is pulmonary tuberculosis forming 70 to 80%, the rest is extra-pulmonary tuberculosis. In 2010 ten million children were orphaned as a result of their parents having died of tuberculosis (WHO, 2013).

In Africa TB affects mainly the young, adolescent and young adults in their reproductive age. Co infection with HIV in sub-Saharan Africa is a big issue that needs to be tackled (WHO, 2008).

TB is strongly associated with poverty. Most of the population of South Sudan are very poor because of the long war. There are scarce data to show the impact of tuberculosis in children in the area. The purpose of this study is to describe the characteristics of children aged 1 month to 14 years with tuberculosis in South Sudan.

Target for Tuberculosis elimination is through reduction of annual incidence to less than one case per million populations by 2050. The milestone en route to elimination will be

reached when there is less than one TB death per 100,000 populations. And many nations can reach that target within one to two decades (Dye *et al*, 2013).

Tuberculosis is a serious infectious disease that continue to cause around 1.8 million deaths annually especially in Sub-Saharan Africa fuelled by HIV/AIDS epidemics. It has become an epidemic of injustice and not only an epidemic of medicine. The control can only be achieved through increased political and financial investment by the industralised nations and sustained political will in the affected nations (Zumla *et al*, 2010)

1.3 Problem Justification

Tuberculosis is a major cause of morbidity and mortality in South Sudan. In 2007 there were 243 cases per 100,000 populations in the whole of Sudan according to WHO. South Sudan alone had 228 cases per 100,000 populations. There were 18,500 new cases and 5,300 deaths annually in South Sudan. The National Tuberculosis and Leprosy Control Programme, Government of South Sudan (NTBLCP/GOSS) reported 4,738 TB cases and 2,513 were new cases of sputum positive infectious type (USAID, 2009). The long civil war in South Sudan had lead to millions of deaths, displacement and loss of assets. Most of the people are very poor and so vulnerable to infections. Although there is no data to show the prevalence of tuberculosis in this age group in South Sudan, a lot of studies had proved that the burden is high in developing countries. In the developing countries about 15% to 40% of all TB cases are in children (Rekeha and Soumya, 2007). Tuberculosis in children shows a sentinel event of recent transmission and is an indication of the efficiency of prevention and control interventions in a nation (Bloch, 1986).

There is little information about the epidemiology of childhood tuberculosis in most parts of the world, particularly in developing nations where tuberculosis rates are highest. In most parts of these nations, the major method of diagnosing tuberculosis is by sputum microscopy and since few children produce sputum and infants don't produce sputum in which the organism can be seen. As a result, tuberculosis in children is vastly under-reported and many children die without being diagnosed or treated (Stark, 2001).

Children aged from 1 month to fourteen years were chosen for the following reasons:

1. Studies have shown that children aged 0 -14 years account for up to one third of all pulmonary tuberculosis cases and so the study population group fall within these high risk group.

2. Young age is a risk factor for tuberculosis since the immune system is not yet fully well developed.
3. Children in this age group are normally under the care of adults and given the fact that there is high transmission of tuberculosis in adults; risk for the children becomes high.
4. The disease in the young can be very fatal causing damage to the brain in case of tuberculous meningitis.
5. Children respond well to anti-tuberculous treatment.
6. Children can form a pool from which future TB cases emerge, so diagnosing and treating them will ensure a TB free nation in the future.

The purpose of this study is to determine the characteristics of children (aged 1 month and 14 years) with tuberculosis in the study site. There was no such study done in South Sudan to show the characteristics of children with tuberculosis in South Sudan. Young children also form a pool from which future cases will emerge so if any latent infections are tackled then there would be less cases in future. The results of this study will be used to formulate policy that would improve intervention for prevention and control of tuberculosis in children in South Sudan thus informing the programmes.

1.4 Research Question

What are the characteristics of children, aged 1 month to 14 years with tuberculosis in public health facilities in Juba, South Sudan?

1.5 Research Objectives

1.5.1 Broad Objective:

To describe the characteristics of children aged one month to 14 years with T.B in public health facilities in Juba, South Sudan.

1.5.2 Specific Objectives are to:

1. Describe the socio-demographic characteristics of the children with tuberculosis.
2. Establish the socio-demographic characteristics of the parents/caregivers of the children with tuberculosis.

3. Determine the level of knowledge of the parents/caregivers of the children with tuberculosis on the cause, transmission and prevention of tuberculosis.

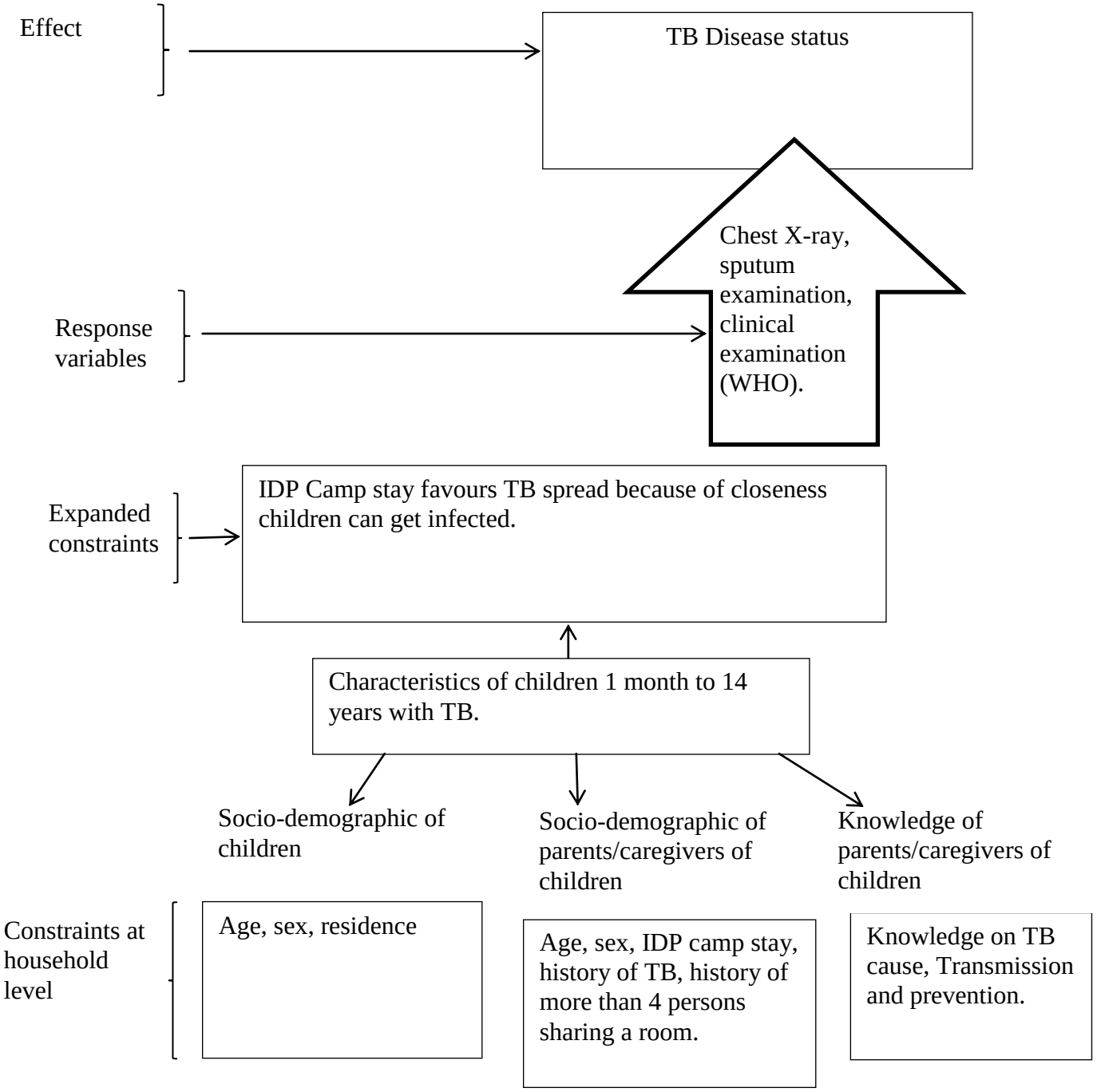
1.6 Definition of Variables

In this study, the variables were the followings:

1. Socio-demographic characteristics of the children refer to their age, sex and Health facilities.
2. Socio-demographic characteristics of the parents/caregivers of the children with Tuberculosis refer to their age and sex, history of staying in an IDP camp, history of Tuberculosis case in the household. Others include history of overcrowding refers to more than four persons sharing a room in a household and lastly the educational level of the parents/caregivers.

3. Knowledge of the parents or caregivers on transmission and prevention of Tuberculosis in this study will refer to their perception about tuberculosis. Whether they are aware or not, of the agent that causes the disease, the mode of transmission of the disease and how to prevent themselves and their children.

CONCEPTUAL FRAMEWORK



CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Risk factors for Tuberculosis in children

Mycobacterium is one of the most successful pathogens of mankind which infected around one third of the world's population (Stewart, 2003). The bacteria have the ability to persist in the form of a long term asymptomatic infection, referred to as latent tuberculosis infection (LTBI). LTBI is central to the biology of the disease (Stewart, 2003). It has been found that over 75% of infants infected with tuberculosis aged less than six months without symptoms will develop clinical disease within the first year of life. And 50% of those between ages 6 and 12 months without symptoms will develop tuberculosis within a year. Young age is associated with severe disseminated disease. In a study on assessing tuberculosis prevalence through population-based survey, some of the risks for tuberculosis were smoking, diabetes, alcohol, malnutrition, overcrowding, indoor air pollution, silicosis, socioeconomic status (SES), HIV status, age and sex (WHO 2007).

(1) Parental Socio-economic and some Environmental Factors.

The American Thoracic Society and the Centres for Disease Control and Prevention (CDC) and Public health experts agreed that screening for LTBI should focus on high risk paediatric populations. To screen low risk population is not cost-effective because a positive tuberculin test has poor positive predictive value (Peter, 1997, Starke *et al*, 1992).

The committee on Infectious disease of the American Academy of paediatricians recommends that children who are new arrivals to the United States from countries with high incidence of tuberculosis should be screened immediately. Children living with HIV infected household contacts should undergo annual screening using TST. And likewise children exposed to adults with other risk factors for active tuberculosis, including homelessness, illicit drug use, incarceration, or migrant from farm workers should have less frequent testing (Peter 1997, Lobato 1998).

In London, a study of 23,536 cases of tuberculosis was followed in a surveillance record from 1999 to 2006, 1370 were under 15 years , that is 5.53% of the cases were children

with a 95% CI of 5.53 -6.13.(Ruwende *et al*, 2010). Risk factors for LTBI in children aged 1 to 5 years was carried out using a case-control study in New York City. They found that crowding, poverty and lower socio-economic conditions were risks for infection in the participants (Saiman *et al*, 2001).

Contacts of tuberculosis patients were traced in Lao's People's Republic. In this study using a cross-sectional survey of villages they found that the awareness of infectiousness among patients and their contacts was 31%. Risky behaviour was common and the risk of LTBI in children was 31%. (Nguyen *et al*, 2009). The study supported contact tracing in remote setting where TB is prevalent. Children's detection rate for tuberculosis should be improved in such settings and education and awareness on infectiousness for patients to reduce transmission are important.

Another study in children aged 0 to 5 years in South Africa used a retrospective descriptive design (Rie *et al*, 1991). They found that children living in poor socio-economic statuses had more morbidity from tuberculosis (Rie *et al*, 1990). Parental education and annual household income showed strongest correlation with case notification rate of childhood tuberculosis. The other factors like crowding, economic status and education of the caregivers were related with case notification rate of tuberculosis in children aged 0 to 5 years (Rie *et al*, 1991).

In India, Singh *et al* (2005) conducted a prevalence study on children under five. The results showed that more children who are in contacts of sputum positive adults were more likely to test positive for tuberculosis. Exposure to environmental tobacco smoke was also cited as a risk factor. The study concluded that children who were contacts of sputum positive tuberculosis patients had more risk for tuberculosis infection and disease (Singh *et al*, 2005).

A prospective hospital-based audit was conducted in Southern Malawi. In this study, 195 children aged less than 5 who were contacts of 161 cases were assessed. The prevalence of tuberculosis infection and disease were 45% and 23% respectively (Sinfield *et al*, 2006). The study concluded that the likelihood of a child to be smear positive increased with the smear positivity of an adult and especially if it is a female (Sinfield *et al*, 2006).

A cross-sectional study conducted in Abuja, Nigeria, studied the children who were contacts of adults with pulmonary tuberculosis to assess the risk of latent infection of these children (Nakaoka *et al*, 2006). The study concluded that risk for infection is affected by age of the child and the smear status of the caring adults. Young age was found to be a high risk especially those less than five years of age. (Nakaoka *et al* 2010).

(2) Socio-cultural Factors

In many studies of the risk for tuberculosis, socio-cultural factors had not been adequately explored. Health culture has an influence on how people perceive a disease. An example in America, where symptomatic people sought chest radiograph to a perception of their susceptibility to the disease and their belief in the unique value of preventive chest radiograph to inform them of the presence of the disease (Rubel and Garro, 1992). In another experimental design, some group of people were shown films on TB and other diseases that may make them more susceptible to tuberculosis infection and to promote the value of preventive care. Eight months after the film, the people sought preventive care from their physician compared to controls that were not shown the film (Haefner and Kirscht 1970).

Success of studies similar to the above led to construction of health believe model (Rosenstoc, 1966; Rosenstoc, 1974).

Health Belief Model

Health believe model (HBM) predicts that the response of people to a threatening illness depends on four factors (Janz and Becker, 1984). These factors are; firstly if the people believe they are susceptible to a condition. Secondly, how severe they perceive the illness. Thirdly, what benefits do they think they can gain through preventive action. And lastly how costly do they perceive the barriers to obtaining that assistance. HBM was later made wider to predict also adherence to treatment without regard to the nature of the illness.

The relevance of HBM to TB care is apparent (Rubel and Garro, 1992). Few studies have sought to assess what motivates a person to take action and when, which is so important an issue in efforts to reduce the transmission of tuberculosis. Mostly HBM was carried out in North America and whether it is applicable in other cultures remains a question.

According to a research conducted in South Texas, delay in tuberculosis care was found to be due to laymen diagnosis of the symptoms to be a condition called "Susto" which was considered not treatable by physician (Rubel, 1960; Rubel and O'Nell, 1984).

In another study in Florida, where Latinos were compared to Blacks on their perception on TB, they found some discrepancies (Jenkins, 1960). Latinos thought TB was a mild, slow-moving, clean, attacking without regard to goodness of an individual and well understood by science. On the other hand the Blacks thought TB is fast-moving, powerful, mysterious and little understood by science. They said TB was a dirty disease that attack bad people.

In Mexico City, tuberculosis patients who were hospitalised complained of social stigma and fear to return home or disclose their tuberculosis status (Rubel and O'Nell, 1984; Herrera *et al*, 1971; Mata, 1985). Both the men and female patients fear to return home for fear of rejection. Most of the participants in this study were illiterate. In East Africa, TB was attributed to witchcraft which led to delay for seeking treatment and also default cases (Ndeti, 1972).

(3) Factors due to the child's condition

Some risk factors which render the child susceptible to tuberculosis infection are due to the followings: The child who is in contact with an infectious adult despite being vaccinated, non-specific symptoms and difficulty in obtaining sputum from a child, vulnerable immune system (the very young, HIV infected, severely malnourished), children with meningitis and milliary TB, children who lack access to health care and children whose parents have TB or HIV/AIDS (WHO, 2013). Poverty, overcrowding and malnutrition and lack of knowledge by the parents about the disease are predisposing factors to tuberculosis infection (Shikha *et al*, 2012).

BCG vaccine

BCG is a vaccine against tuberculosis that is prepared from a strain of the attenuated (weakened) live bovine tuberculosis bacillus, mycobacterium bovis that had lost its virulence in humans by being specially cultured in an artificial media for years. The bacilli have retained enough antigenicity to become a somewhat effective vaccine for the prevention of tuberculosis in humans.

In Turkey, a study by Soysal *et al*, investigated some 979 children who were contacts of adult sputum positive tuberculosis patients (Soysal *et al*, 2005). They proved through this study that BCG not only protects against TB disease but also against TB infection.

In a study in South East Asia, Sub-Saharan Africa and Western Pacific Regions, BCG was found to be a cost-effective intervention in childhood tuberculosis and should be retained in high-incidence countries to supplement chemotherapy for tuberculosis (Trunz *et al*, 2006).

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study Site

This study was conducted in Juba South Sudan. Juba is the capital of Central Equatoria state in South Sudan and the capital of The Republic of South Sudan. Juba city is composed of Juba municipality and the surrounding suburbs. The municipality consists of three areas and these are Juba town, Kator and Munuki. After the Comprehensive Peace Agreement, the hospital in Juba, Juba Teaching Hospital, became the referral hospital of South Sudan (ICRC, 2010). The hospital has a centre for tuberculosis care. The cases for tuberculosis were diagnosed in the hospital and treatment continued in the other facilities which were convenient to the patient in terms of distance. There are other two facilities for TB care besides Juba Teaching Hospital, and these are Munuki Primary Health Care Centre and Kator Primary Health Care Centre. The facility at Juba Teaching Hospital has one medical officer, one clinical officer, one laboratory technician, two lab assistants and a store-keeper. Munuki PHCC has one clinical officer, two laboratory assistants and two nurses. Kator PHCC has one clinical officer, two nurses and two laboratory assistants. More than half the population of South Sudan seek treatment in Juba, it being the capital City. This made Juba a suitable area to conduct this study and in this case a hospital study was more suitable because some of the patients came just to seek formal medical attention and travelled back to their villages. Juba is where most of the qualified medical staff is located so this attracts most patients to come and seek medical care. This made the results of this study to be generalised to only those who sought medical care at the public health facilities which is one of the limitations of this study.

The health system in South Sudan has been destroyed due to the long civil war which ended after the comprehensive peace agreement was signed on 9th January 2005 (Health Policy for GOSS 2006). The health system has four basic levels of administrative structure which include:

1. The community (PHC unit),
2. The first referral (PHCC),
3. The second referral hospital,
4. The County health department.

A new political landscape has been set for repairing the damage and more especially the health system. Basic primary health care is the cornerstone of the health system here. Evidence showed that, 90% of the population of South Sudan live below a dollar a day. Poverty is a very striking feature. Displacement, depletion of assets and limited access to social services has led to poverty (Health Policy for GOSS, 2006). Tuberculosis is a major cause of morbidity and mortality in South Sudan (USAID, 2009). The control of tuberculosis is limited and only 25% of the total population is covered (UNDP, 2010). The burden of TB in children in Southern Sudan is not known because no studies had been conducted in this age group to my knowledge. More knowledge is needed for Tuberculosis control activities so that the Ministry of Health can plan for more Public Health facilities to offer care.

3.2 Study Design

This study was a hospital-based cross-sectional study. The study set out to determine the characteristics of children, aged 1 month to 14 years, with tuberculosis in public health facilities in Juba.

3.3 Study Population

All the children, aged between 1 month and 14 years, with tuberculosis at the health facilities and whose care-givers gave written informed consent participated in the study. These children had been diagnosed and on anti-tuberculous treatment. Diagnoses of these children depended on the WHO guidelines (WHO, 2000) and were as below. For those children who were too young to produce sputum, diagnosis depended on:

- A child who was sick and had a history of contact with a tuberculosis suspect or confirmed case.
- A child who did not recover from an attack of measles or whooping cough
- A child with loss of weight, cough and fever did not respond to antibiotic therapy for acute respiratory disease.
- A child with abdominal swelling, hard painless mass and free fluid.

For those children who are older and capable of producing sputum,

- A chest radiograph
- Sputum microscopy for AAFB.

In South Sudan, those children who are unable to produce sputum were diagnosed clinically depending on the WHO guidelines meanwhile those who can produce sputum undergo sputum microscopy and chest x-ray. The children in the study were mainly pulmonary tuberculosis.

3.4 Inclusion and Exclusion Criteria.

3.4.1 Inclusion Criteria

1. A child aged 1 month to 14 years of age on treatment at the health facility at the time of the study.
2. The child diagnosed as a tuberculosis case.
3. An informed consent obtained from the parent or care-giver.

3.4.2 Exclusion Criteria

1. The child whose diagnosis was a condition other than tuberculosis.
2. A child who was eligible but his/her mother or parent/care-giver refused to give informed written consent.
3. The child not aged between 1 month and 14 years.

3.5 Sample Size Determination

The sample size was determined using the following formula (Lwanga *et al*, 1991):

$n = Z^2 \times P\ (1\text{-}P)\ /d^2$.

Where,

n is the minimum sample size.

Z is the standard normal deviate, corresponding to 95% confidence level,

P is the estimated prevalence of the risk in the population (=31%) (Nguyen *et al*, 2009 in Lao People's Democratic Republic).

d is the degree of precision set at ±5%

On substitution of the values in the formula, the sample became 328 children. A total of 330 children were recruited to participate in the study.

3.6 Recruitment of Participating Children

All the children who were attending the three purposely selected public health facilities during the study period were proportionately included. It had been anticipated to get more children with tuberculosis so that they would be sampled but this was not the case.

Therefore, all children who met the inclusion criteria and whose parents/guardians consented for them to participate were recruited into the study.

The participating children according to health facilities are presented in Table 1.

Health facility	No. of children	Percentage
Juba	194	59
Munuki	82	25
Kator	54	16
Total	330	100

3.7 Data Collection

Data collection took five months, from August to December 2012. The enrolment of the participants took five months.

Both Quantitative and qualitative methods were utilized.

Questionnaires consisted of both open-ended and close-ended questions, interview guide for key informants, focus group discussion guide and a tape recorder for the discussions were used for data collection. These tools were pre-tested prior to data collection and this was carried out at Alsabbah children's hospital which is a public health facility.

Quantitative data were collected through questionnaires while qualitative data were collected through focus group discussion (FGD). The caregivers of the children with tuberculosis participated in the FGD.

Research assistants were trained by the principle investigator on how to collect the data. Training continued for at least two days and the nurses trained were certified nurses with at least two years of experience working at the T.B. clinics. The information that the questionnaires yielded were explained clearly to the research assistants.

At the same time, two research assistants who were qualified certified nurses with at least two years of experience at the T.B. clinic were trained for at least two days on how to conduct focus group discussions. The mothers who participated in these FGD consisted of 8 to 12 members. A total of nine FGD were conducted. Two of these groups composed of male members, the rest composed of females.

The key informant interviews were conducted by the principle investigator, and those who were interviewed included the directors of the clinics, the head nurses in charge of T.B care in the clinics, the directors of the facilities and the senior medical officers of the facilities where the data were collected. These key informants formed the point of entry to the facilities. After interviewing them the study was conducted in the respective facility.

3.8 Data Analysis

3.8.1 Data Processing and Analysis

The questionnaires were edited before data entry and the frequencies ran to verify outliers. The data was then stored in a computer under a password and backed on an external hard drive. Each entry had a unique number for the purpose of protecting the study participants. The questionnaires were then filed in a safe cabinet and verification of results was done whenever necessary. The data was analyzed using Epi Info 3.5.4 version.

Data presentation was in form of tables and figures. Appropriate descriptive statistics such as, means, proportions, were determined during the analysis.

Qualitative data from FGD were arranged into themes and then analysed manually.

3.8.2 Quality Control

Given the importance of collecting this information accurately, all aspects of quality assurance were adhered to. To ensure quality of data, some measures of quality control were carried periodically and these included:

- Monitored the procedure adopted by the research assistant to ensure that these conformed with the stipulated protocols;
- Carried out repeated checking of the filled questionnaires to check on the accuracy of the research assistant where necessary;
- Checked the data collection form to ensure completeness and neatness and to make sure that the appropriate measures had been taken.

Keeping daily log of important or unusual: principal researcher kept a daily log of any happening which warranted noting or required subsequent attention.

3.9 Minimization of errors and biases

1. The research assistants were trained on data collection procedures.

2. The data collection tools were pre-tested.
3. The principal investigator ensured that the research assistants followed the standard procedure for collection of the data by checking on the interviews as they were conducted and participated in it as well.
4. The principal investigator edited filled questionnaires on daily basis.

3.10 Ethical consideration

Approval of the study was sought from Kenyatta National Hospital/ University of Nairobi Ethical and research Committee.

Permission to conduct the study was sought from the ethical committee of the Ministry of Health, Government of South Sudan as well as from the health facility administrators.

A written informed consent was obtained from each participant after being explained what the study entailed.

There were no risks involved to the clients in this study and any one who wished to withdraw his/her consent did so without any penalties.

All the information that was given by the clients was treated with confidentiality. No names were mentioned from the information gathered. All the information was used under strict confidentiality.

3.11 Utilization of the findings

This study was a thesis as partial fulfilment for the master of public health degree of the University of Nairobi. The findings were shared by colleagues and staff in the school of public health and other students from institution of higher learning. Hopefully the results of the study would be adapted in the National Tuberculosis Control Program of South Sudan.

3.12 Study limitations

1. It was very difficult to tell with certainty if the risk preceded the infection or not, the study being a cross-sectional study and this was minimized by recommending for future further studies on the risk factors for tuberculosis in children.
2. There were biases for example information bias since the questionnaire was only in English language which was translated to colloquial Arabic language to the

parents/caregivers. Information bias was minimized by training the research assistants.

3. Furthermore, choosing participants from the public health facilities made the results difficult to generalize to the general population.
4. These limitations were minimized by recommending for a future community based study for the risk factors for tuberculosis in children in South Sudan.

CHAPTER FOUR

4.0 RESULTS

4.1 Socio-demographic characteristics of the children

The children who participated in the study were 330. The ages ranged from 2 months to 14 years with a mean age of 56 months, a median of 48 months and a mode of 60 months.

A total of 162 (49%) females and 168 (51%) males participated in the study (figure 1).

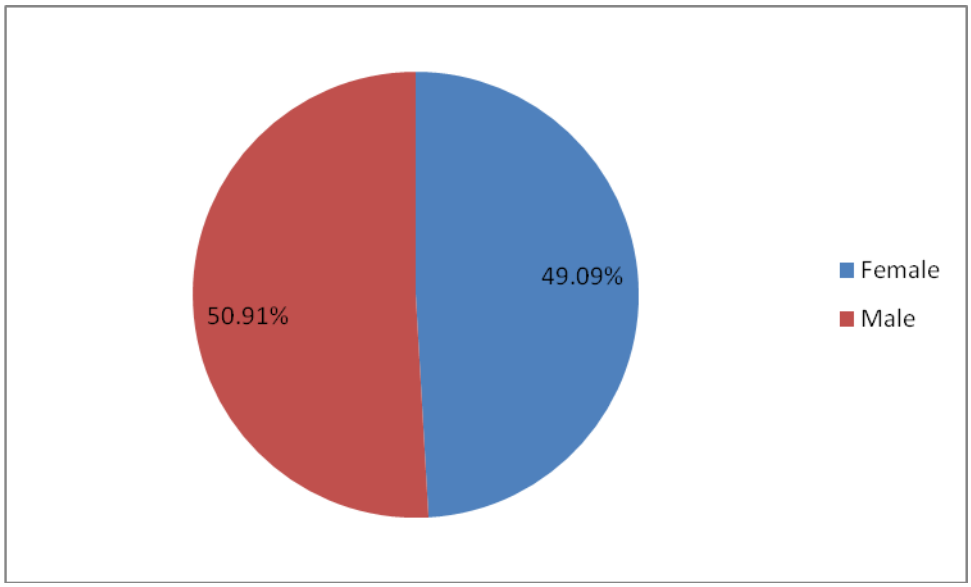


Figure 1: Sex distribution of children

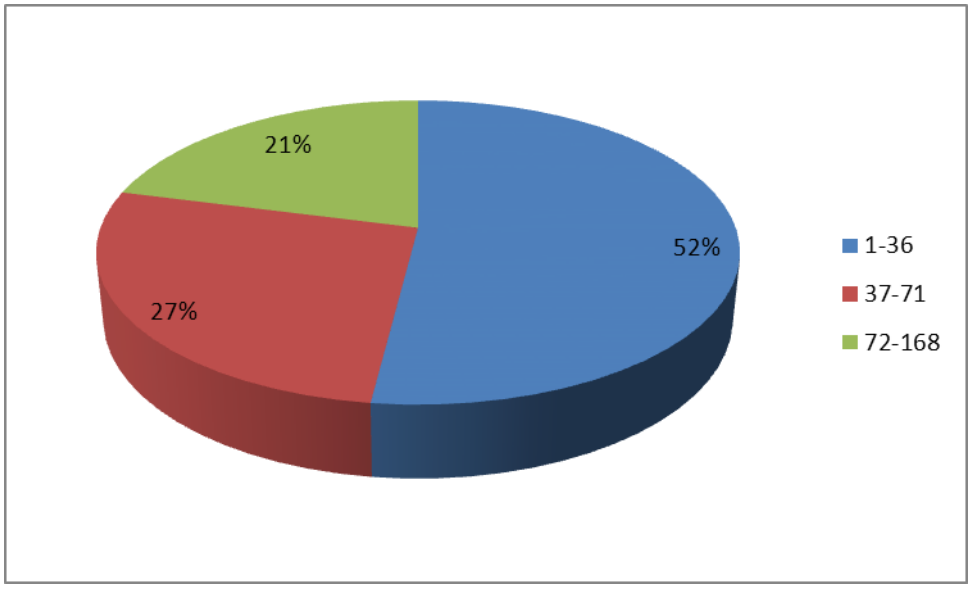


Figure 2: Age distribution of the children.

Fifty-two percent of the children were in the age group of 1 to 36 months (figure 2). Most of the children in the study were from Munuki PHCC. (Figure 3).

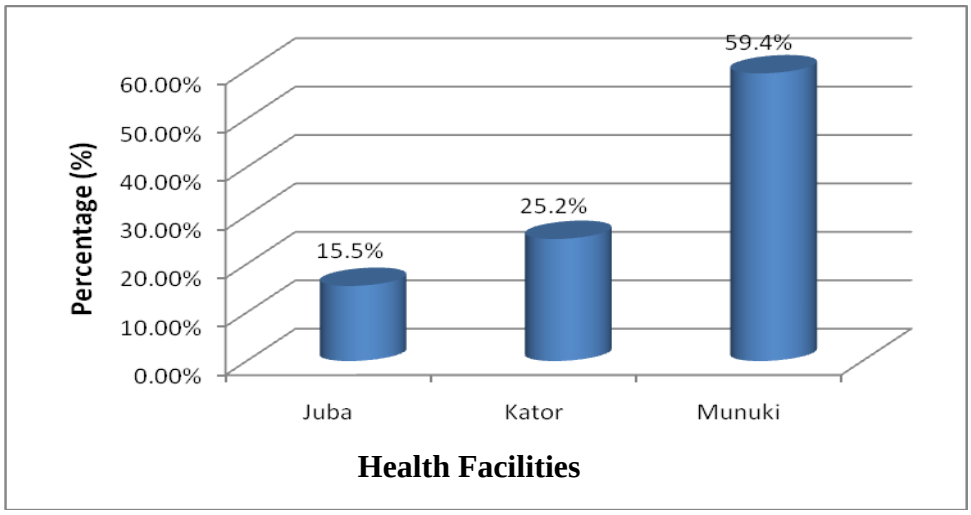


Figure 3: Health facilities of children

4.2 The socio-demographic characteristics of the parents/caregivers

Age.

The age of the parents/caregivers showed a mean of 32, a mode of 30, and a median of 30 years and a range of 17 to 70 years.

Sex

The parents/caregivers of the children were mostly female (69%), figure 4.

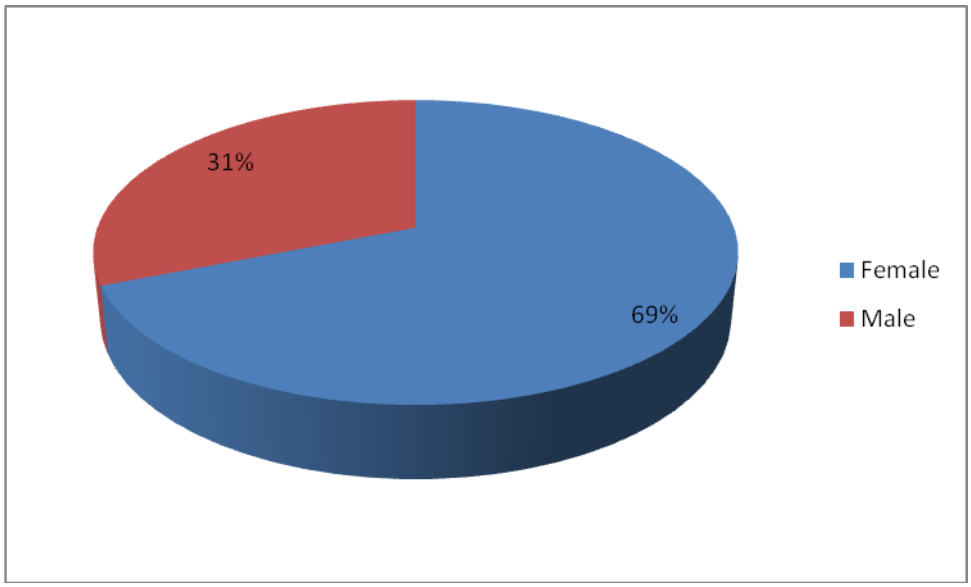


Figure 4: Sex distribution of the parents/caregivers of children

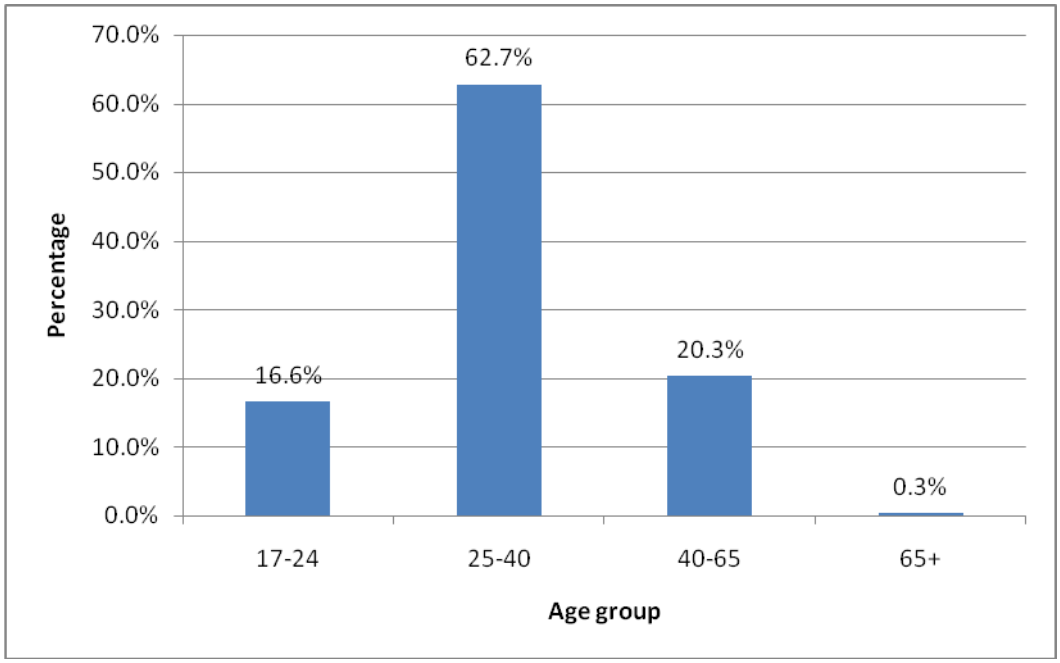


Figure 5: Age distribution of parents/caregivers of children

4.2.2 History of staying in an IDP camp.

Ninety-nine (30%) respondents admitted to have stayed in an IDP camp while the remaining 231 (70%) had not stayed in IDP camp. Asked if they had a history of TB reported in the household, 156 (47.3%) answered in the affirmative.

Parents/caregivers who stayed in an IDP camp and had a history of tuberculosis were 63(64%). Those who did stay in an IDP camp but had no history of tuberculosis were 36(36%), table 2.

Table 2: History of caregivers staying in IDP camp with history of TB reported in the household

		History of caregivers staying in IDP camp		
		Yes	No	Total
History of TB reported in the household	Yes	63 (64)	36 (36)	99
	No	93 (46)	138 (54)	231
Total		156	174	330

In parentheses are percentages

4.2.3 History of tuberculosis reported in the household of the parents/caregivers.

The data showed that 53% of the parents/caregivers reported history of tuberculosis in their households, figure 6.

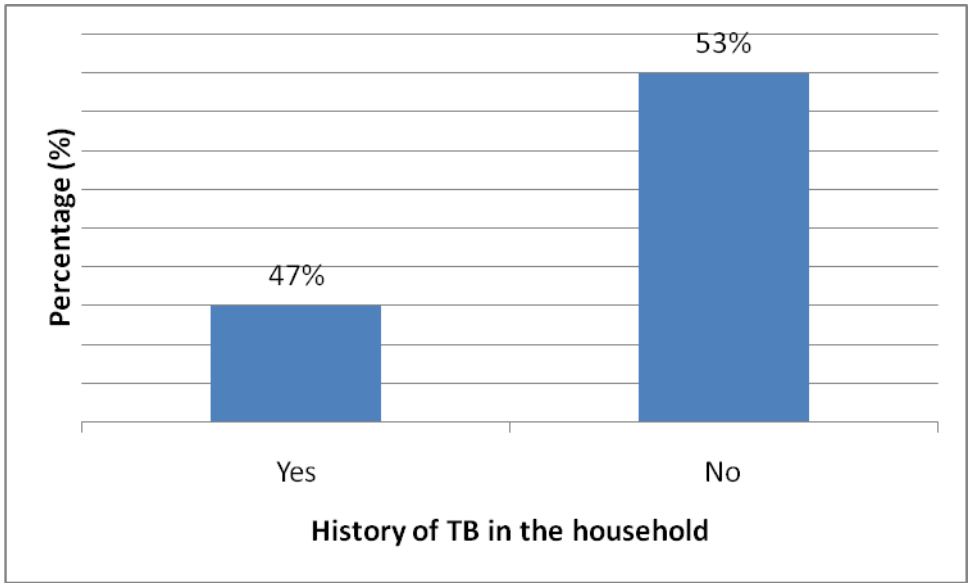


Figure 6: History of reported TB in the household of parents/caregivers

4.2.4 History of overcrowding in the households.

The study showed that parents/caregivers who had a history of overcrowding and history of tuberculosis in the household were 122(48%). Those who had history of overcrowding and had no history of tuberculosis in the household were 132(52%), table 3.

Table 3: History of overcrowding with history of TB reported in the households.

		History of TB in the household		
		Yes	No	Total
History of overcrowding	Yes	122(48)	132 (52)	254
	No	34 (44.7)	42 (55.3)	76
Total		156	174	330

In parentheses are percentages

4.2.5 Educational level of parents/caregivers.

The parents/caregivers who were educated were 33.9% and those not educated were 66.1% (table 3).

The parents/caregivers who were educated and had a history of tuberculosis in the household were 49.2% and those educated and had no history of tuberculosis were 50.8%, table 4.

Table 4: Showing educational level of the participants and history of Tuberculosis in the household.

		History of TB in the household		
		Yes	No	Total
Educational level of parents/caregivers	Educated	57(50.8)	55(49.2)	112
	Not educated	99 (45.4)	119 (54.6)	218
Total		156	174	330

In parentheses are percentages

The data were further analysed for association of history of staying in an IDP camp, history of overcrowding and educational level in relation to history of TB case in the household (Table 5). History of staying in an IDP camp showed a statistically significant association with history of TB case in the household (p= 0.00015).

Table 5: Association of history of staying in an IDP camp, educational level and history of overcrowding.

Characteristic	**Estimated RR**	**CI (95%)**	**p-value**
History of caregivers staying in IDP camp	1.59	1.27, 1.96	0.00015
Education level	0.89	0.71, 1.12	0.4
History of overcrowding	1.07	0.81, 1.42	0.7

4.3 Knowledge of the parents/caregivers on Tuberculosis

The study also revealed that the parents/caregivers knowledge on tuberculosis was very low. The question on cause of Tuberculosis was given the participants to choose from the options to avoid giving out the correct answer when reading and translating. The knowledge was assessed categorically whether they know the agent which causes tuberculosis, the mode of transmission and how to prevent and control the spread of the disease as shown in Table 6. Those who knew the cause of tuberculosis were 23%. 32% knew about transmission and 21% knew about the prevention.

Table 6: Knowledge of respondents on Cause, Transmission and Prevention of Tuberculosis.

	Knew	**Did not know**
Causing Agent	75 (23)	255 (77)
Mode of Transmission	106(32)	224 (68)
Mode of Prevention	69 (21)	234 (79)

In parentheses are percentages.

The overall knowledge level was assessed in the parents/caregivers of the children and was that those who had good knowledge were only 3%.Those with adequate knowledge were 16% and those with inadequate knowledge were 19%. Slightly less than two-thirds (62%) of the parents/caregivers had no knowledge (62%) (Table 7).

Table 7: Overall level of knowledge on TB among Parents/Caregivers

	Number (%)
Good knowledge	10 (3%)
Adequate knowledge	53 (16)
Inadequate knowledge	63 (19)
No knowledge	204 (62)

These results concurred with that from the nine FGD conducted where the groups reached a consensus on the cause of tuberculosis.

The participants were at first reluctant to freely air their views on the subject. As the discussion went on, they felt free and could answer to what tuberculosis disease is. They said TB means long cough and each gave a name in their language which means cough, cited few were: "yoka", "ran nekol", lomain, ichwe, taak, kido, guang, oyello, ipele, lebong, adravu agaru, ridhi, twangwol, ayala, kel, jiola

They all reached a consensus that TB had a cause.

One participant said that *"TB is caused by trauma to the chest and to treat it is by cutting the chest and letting the bad blood out"*. Another participant said that *"TB is caused by bad wind, cold weather and eating okra".* This was not a consensus; it was an opinion by some of the participants.

The results from the questionnaire were confirmed by the finding from the FDG, where knowledge on tuberculosis regarding the causative agent was very low.

The interviews results also revealed that knowledge on transmission of tuberculosis was low. The group discussion results showed that most of them were not aware about the mode of transmission. Some of participants agreed that TB is transmitted from a sick individual when sharing a room, sharing food or drink with them from the same utensil. However, most of the participants did not know about TB. They thought TB is a disease in the family and that one can get from a family member to whom one is blood related.

The participants all agreed they had traditional treatment for tuberculosis disease. Some said that there are some special herbs used for treating tuberculosis. While others claimed TB could be treated by drinking ostrich oil, eating meat and drinking fresh. One participant said that *"treatment for TB is giving the sick person donkey milk"*. A second participant went further to say that "*to treat TB the sick person has to be given a python's oil".*

The discussion showed the parents/caregivers of the children who participated had low knowledge on tuberculosis disease which is confirmed by the qualitative data which also showed low level of knowledge on the disease, 23% of them knew the agent that causes tuberculosis, 32% knew the mode of transmission and 21% knew how to protect themselves from the diseases, table 5.

CHAPTER FIVE

5.0 DISCUSSION

5.1 Socio-demographic characteristics of the children

This study revealed that the children mostly affected with Tuberculosis infection were in the age group 1-36 months comprising 51.8% of the total participants. The age of the children were distributed with a mean of 56 months, mode of 60 months and a median age of 48 months and a range of 2 months to 14 years.

In another study using retrospective review of TB records and chest radiographs of children born in Cape Town in 1999 and diagnosed with tuberculosis between 1999 and 2004, the peak incidence of the disease was in children aged 12-23 months (Moyo, *et al*, 2010). The study showed that young age increases vulnerability to tuberculosis infection.

Another study also confirmed the fact that young age coupled with contact with sputum positive adult contact favours tuberculosis disease transmission. (Singh *et al*, 2003).

In a screening study in India by Pandhi *et al* (2004), out of 142 patients, 68 were children ranging from the age of 9 months to 14 years. In this study, the median age was 48 months that is to say below 5 years.

This study also revealed that 49% of the children who participated were females. A household contact study in Gambia, in which 384 children below 5 were studied, showed that the median age was 2 years and 48% of the children enrolled were girls. (Christian *et al*, 2003). However, this did not show any significant difference between sex of a child and getting tuberculosis disease. Any child who is in contact with an adult case of tuberculosis had an increase chance of getting infected.

In Tanzania, a study in children with tuberculosis showed that a high proportion of tuberculosis was in the age group below 24 months, 45.9% of the total participants (Njau and Aboud, 2010). All the above studies had shown that young age made a child vulnerable to tuberculosis if exposed to a tuberculosis infectious case.

5.2 Sociodemographic characteristics of the parents/caregivers

The number of parents/caregivers was 228 females and 102 males. The parents/caregivers were mostly in the age group of 25-40 years; 62.7%.

In this study the parents/caregivers characteristics which were significant as far as tuberculosis infection in their children were concerned was history of staying in an IDP camp giving an estimated relative risk of 1.59 and 95% CI (1.27, 1.96), and a p-value of 0.00015. This showed that there was an association between a caregiver staying in an IDP camp and their children getting infected with tuberculosis. The conditions in the camps favoured transmission of the disease.

5.2.1 The role of contact in the spread of Tuberculosis

Other factors like presence of an adult sick with tuberculosis in the household was not significant as most of those who participated in the study reported they had no case at home, fifty three percent. An explanation for this finding could mean the children could have contacted the disease from a source outside home. Other explanations could mainly be due to the study methodology used; a study where children contacts of the adults with tuberculosis are screened will reveal more significant results.

In this study the parents/caregivers were mostly females, they formed 69% of the total caregivers who participated. This showed that most of the children could have gotten the infection from a female contact.

In a similar study in Malawi, using a prospective hospital-based audit, conducted over a 17 month period showed that a child was most likely to get infected if their contact was a female with an OR of 2.25, 95% CI of 1.19- 4.27, p value of 0.01.(Sinfield, *et al,* 2006). Most of caregivers admitted they had a TB case in the household.

A screening study in India revealed that family history of tuberculosis was confirmed in 28(41.2%) of the cases (Pandhi *et al*, 2004). In Tanzania, a study in children with tuberculosis confirmed history of positive TB contact among the risk factors for tuberculosis (Njau and Aboud, 2010). In a case-control study carried out in 44 non-private hospitals in Malawi treating TB patients, it was found that there was a high prevalence of tuberculosis among households of index TB patients, around 56 members out of 2766 TB patients (frequency of 2024/100000) develop tuberculosis within a year compared to controls with a frequency of 343/100000 (Claessens *et al*, 2002).

A prospective study in Angola enrolled children less than 5 years of age who were contacts of adult TB cases, out of a total of 142 children, 70(56.6%) were active TB cases (Fortunato and Sant Ann, 2011)

5.2.2 Role of overcrowding in the spread of Tuberculosis

History of overcrowding in the households of these children did not show significant association in the spread of tuberculosis in these children.

This study revealed that those parents/caregivers who responded that they had more than four people sharing a room in their household and had a history of tuberculosis constituted 48%. This study showed that over crowding had no role in the spread of tuberculosis disease in the study participants. Such a finding could be due to factors like the design of the study, so a community survey could have been better. There could have been a recall bias when the participants were asked if they remembered more than four persons sharing a room in their household.

In a study in Italy, which is an example of an industrialized nation, tuberculosis disease was found to be common in subgroups like immigrants from high endemic countries, ethnic minorities, refugees and the homeless (Marino *et al*, 2013). This confirms the fact that overcrowded conditions favours the transmission of tuberculosis infection.

Another study in Greece by Syridou *et al* (2012), retrospectively reviewed medical records of patients aged less than 14 years. The study concluded that tuberculosis epidemiology and drug resistance was influenced by the increased influx of immigrants from areas where tuberculosis has high prevalence.

In North Carolina, a study using a retrospective cohort and cross-sectional study in a public health paediatric department clinic, 88.3% of the children with LTBI were children of non-white whose parents were foreign born (Stout *et al*, 2006).

The above studies confirmed the fact that there is an association between over crowded conditions and tuberculosis disease transmission.

5.2.3 The role of education in Tuberculosis disease

The parents/caregivers who were educated were 33.9% and those not educated were 66.1%.Educational level of the caregiver did not show significant association with occurrence of tuberculosis in the children in this study because as the data showed, those

who are educated and had a history of tuberculosis in the household are 49% and those who are educated and had no history of tuberculosis were 51%. There was no an association between educational level and tuberculosis disease. This study revealed low educational level for the parents/caregivers. A similar study in South India, showed that low educational level was among the significant risk factors for tuberculosis with an OR of 0.3, 95% CI of 1.11-0.82.(Shetty *et al*, 2006).

In a KAP study in Nigeria assessing knowledge on tuberculosis, it was found that a high percentage (67.8%) of the respondents have not heard of contact tracing and only 37% knew tuberculosis was caused by a bacteria (Iomotomo *et al*, 2012).

5.3 Knowledge of the parents/caregivers on Tuberculosis disease

This study has revealed that the knowledge of the parents/caregivers on Tuberculosis disease was very low. This calls for a health education programme to be strengthened as afar as Tuberculosis disease is concerned. The parents/caregivers who knew the causative organism for the disease were only 23%, 32% knew about the mode of transmission and only 21% knew about the prevention against the disease. This finding concurred with FGD findings which also showed low knowledge of the parents/caregivers on Tuberculosis. The study showed that there was no association between parents/caregivers knowledge on Tuberculosis and their children being sick of the disease. Most of those children who participated in the study had parents/caregivers who had inadequate knowledge of the disease.

CHAPTER SIX

6.0 CONCLUSIONS

This study showed that slightly over a half (52%) of the children who had TB and participated in the study were in the age group 1 month to 36 months; 52%. There were slightly more male children than females (51% verses 49%).

In this study most of the parents/caregivers were in the age group 25 to 65 years (62.7 %) and most of them were females (69%).

Parents/caregivers who stayed in an IDP camp and had history of tuberculosis in the household were 63(64%). Those who stayed in an IDP camp and had no history of tuberculosis in the household were 36 (36%).

Almost a half (47%) of households were said to have had history of tuberculosis in the household.

About a half (48%) of households with a history of overcrowding also reported history of tuberculosis in the household.

History of parents/caregivers staying in an IPD camp was significantly associated with a history of TB reported in the household.

A percentage of 33.9% of the parents/caregivers were educated compared to 66.1% who were not educated.

History of overcrowding in the household did not show any statistically significant association with tuberculosis occurrence in the household. Similarly, educational level of the parents/caregivers did not show significant association with tuberculosis occurrence in the household.

Level of knowledge on knowledge of tuberculosis disease regarding agent, transmission and prevention among parents/caregivers was found to be very low.

CHAPTER SEVEN

7.0 RECOMMENDATIONS

1. Childhood tuberculosis is serious in the 1 to 36 months age group. They should all be screened and those found positive treated.
2. Contact tracing of adults with tuberculosis should be integrated into tuberculosis control program as an entry point and contacts should be followed and screened to reduce the burden of tuberculosis
3. The Ministry of Health should implement Health education program to communicate the importance of proper housing and ventilation to prevent Tuberculosis.
4. Public Health interventions like Health Education Program should be implemented in the IDP camps to prevent the spread of Tuberculosis.
5. Further studies should be conducted in South Sudan in the age group 1 to 36 months on the following areas;

   (a) The characteristics of children with tuberculosis and the immunization coverage for tuberculosis.

   (b) The association of malnutrition and tuberculosis in children.

   (c) The association of HIV/AIDS and tuberculosis in children.

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Appendices

Appendix 1: Questionnaire

Topic: Characteristics of Children aged 1 month to 14 Years with Tuberculosis in Public Health Facilities in Juba, Southern Sudan.

Information for Identification:

Date of interview D……..M…….Y……

Name of interviewer……..

Identification No.…….

SOCIO-DEMOGRAPHIC INFORMATION OF THE CHILD AND CARETAKER:

I. **Personal information**:

1 .Sex: ……

2. .Age of the child: ---------- (months/years)

3 .Health facilities of the child: .....

4. Sex of child: Male ……Female

5. Age of caregiver ……

6. Sex of Caregiver: Male ( ) Female ( )

7. Occupation of the parent/caregiver, skilled ( ) unskilled ( )

8. Educational level of the caregiver: None( ), Primary ( ), intermediate ( ), Secondary ( ), college ( ).

II. **Environmental Factors**

9 . Have your family ever stayed in an IDP or refugee camp before? Yes ( ), No ( ).

10. How many people share a room in your household? .....

11. (a) Does your child share room with grown-ups in the house? (Yes)…. (No)

(b) If yes, how many people share the room with the child? .....

12. Has anyone in your household ever had T.B? Yes ( ) No ( )

If yes, did they get treated? Yes( ) No ( ).

III. **Socio- Cultural Factors**

13. What is TB in your culture?

.....

14. Is there any traditional treatment for TB? Yes ( ) No ( ).

15. If yes, what is it?.....

IV. **Knowledge on T.B.**

16. What is TB?

1. TB is a disease due to: witchcraft ( )

2. Germs ( ) mycobacterium tuberculosis ( ).

3. Other (specify).....

4. Do not know.

17. (a) Do you know how TB is transmitted? Yes ( ) No ( ).

(b) If yes, how is it transmitted? ……

18. How would you protect yourself and your child from getting infected with T.B?

…….....

V. **Tuberculosis Diagnosis**

19. When was your child diagnosed with T.B.?.....

Appendix 2: Focus group discussion (FGD) guide

Q1. What is TB in your culture?

Q2. Is there any traditional treatment for tuberculosis?

Q3. How does a person get tuberculosis disease?

Q4.how does a person protect oneself from getting infected with tuberculosis disease?

Q5. Have your family ever stayed in an IDP camp?

Q6. How many people share the room in your household?

Q7. Has anyone ever had tuberculosis in your household?

Appendix 3: Consent explanation for mother / caregiver of the child

Study on "The characteristics of children with tuberculosis in Juba, South Sudan"

I, Linda Levi Enoka, am a postgraduate student at University of Nairobi pursuing a master's in Public Health (MPH) degree programme.

Tuberculosis is a serious disease in children and can cause permanent disabilities in children or even can kill if not treated on time. The best thing is to prevent our children from being infected. So by knowing the risk factors, we can be able to prevent this vulnerable group from infection and ensure a healthy nation. You are free to consent or not to consent to participate in this study. You also have the right to withdraw from the study any time you feel like. There are no punishments for stopping participation.

I would like to request you and your child to participate in this study. If you accept to take part in the study, then you will be asked some questions regarding your self, your child and about your home.

There are no direct benefits of this study to your child but the information you provide will be used by policy-makers in planning for preventive measures against tuberculosis in children and formulate policy to improve intervention against tuberculosis disease for children in the area.

Any information you give will be treated in confidence. Your names will not appear on forms. The information you provide will only be used for the purpose of the study. No names will be mentioned. Your confidentiality will be treated with utmost respect.

There are no risks involved in your child participating in this study.

If you feel like withdrawing from the study while being interviewed, you are free to do so without any penalty. You and your child will continue to get the services you are entitled for even if you decide to participate or not participate in the study.

In case you have any questions related to this study, you can either contact me ..... me on the following numbers +249911117425/+249955680750 or KNH/UoN ERC, P.O BOX 20723 - 00202, Tel 729300-9 or my supervisors: Prof. E.N. Ngugi and Dr. Dismas Ongore, at the School of Public Health, University of Nairobi through the secretary on this number +254202724639.

Appendix 4: Consent form

I have been explained to about the study, its purpose and what it entails and also given opportunity to ask questions and I hereby AGREE / DISAGREE to participate in this study.

I have understood the objectives of this study and have agreed to participate willingly.

Participant's signature or fingerprint…….. Date……..

Witness/ Research Assistant: Signature …….. Date ……..

Appendix 5: Consent form for the key informants

Title of the study: To determine the risk factors associated with tuberculosis infection in children aged 1 month to 14 years: A cross-sectional study in Juba, South Sudan.

I, Linda Levi Enoka, am a postgraduate student at University of Nairobi pursuing a master's in Public Health (MPH) degree programme.

I am requesting you to participate in this research by providing some information on T.B. in children in South Sudan and what the government is doing about it.

Purpose: Tuberculosis is a serious disease in children and can cause permanent disabilities in children or even can kill if not treated on time. The best thing is to prevent our children from being infected. So by knowing the risk factors, we can be able to prevent this vulnerable group from infection and ensure a healthy nation. You are free to consent or not to consent to participate in this study. You also have the right to withdraw from the study any time you feel like. There are no punishments for stopping participation.

Benefits

The results of this study will help in planning preventive measures against tuberculosis in children and formulate policy to improve intervention against tuberculosis disease.

Confidentiality

Any information you give will be treated as confidential. No names will be mentioned. Your confidentiality will be treated with utmost respect.

Risks

There are no risks involved in this study.

Withdrawal from study

If you feel like withdrawing from the study, you are free to do so. There will be no punishments for anyone who withdraws from the study.

In case you have any questions related to this study, you can either contact me on the following numbers +249911117425/+249955680750 or KNH/UoN ERC, P.O BOX 20723 - 00202, Tel 729300-9 or my supervisors: Prof. E.N. Ngugi and Dr. Dismas Ongore, at the School of Public Health, University of Nairobi through the secretary on this number +254202724639.

If you have any questions regarding this study that you were not clear of, you are free to ask them.

Appendix 6: Consent form

I have been explained to about the study, its purpose and what it entails and also given opportunity to ask questions and I hereby AGREE / DISAGREE to participate in this study.

I have understood the objectives of this study and have agreed to participate willingly.

Participant's signature or…….. Date……..

Principal investigator: Signature …….. Date ……..

Appendix 7. Consent form for the participants of FDG.

We have been explained to about the study, its purpose and what it entails and also given opportunity to ask questions and we hereby AGREE / DISAGREE to participate in this study. We have decided to keep confidentiality of whatever we have have discussed as a group and not reveal each others disclosure of whatever we discussed.

We have understood the objectives of this study and have agreed to participate willingly.

Participants' signature or fingerprint…….. Date……..

Witness/ Research Assistant: Signature …….. Date ……..

Appendix 8: Map of the republic of South Sudan

Appendix 9: Approval

REPUBLIC OF SOUTH SUDAN

MINISTRY OF HEALTH

To: Linda Levi Chama

University of Nairobi, Kenya

Date:23rd July, 2012

Dear Linda

RESEARCH APPROVAL LETTER

The Characteristics of Children with Tuberculosis in Health Facilities in Juba, South Sudan

I am Writing in response to the request for authorization for the study on ***''The characteristics of Children with Tuberculosis in health facilities in Juba South Sudan''.*** TB is one of major public Health concern in our emerging country and posing a threat of Health of South Sudanese Children. This study for sure will contribute to improvement of TB services in Health facilities in Juba South Sudan.

After close review of the proposal, I am glad to inform you that the Ethical Committee at the Ministry of Health, Republic of South Sudan has approved the study. Please, Keep the MOH-RSS informed on the progress of the study.

I look forward to the report and recommendations that will be generated from the study. Note that the study should not be published without the consent of the MOH-RSS.

Good luck and don't hesitate to get in touch should there be any queries

Yours Sincerely

23rd July 2012

Dr. Richard Loku Lino

Director Research, Monitoring and Evaluation

Ministry of Health, Republic of South Sudan,

Cc: Undersecretary, MOH-RSS

Cc: Director General Planning and Coordination

Cc: Director General, Community & Public Health, MOH-RSS

Cc, Director General, Training &Professional Development, MOH-RSS

Headquarters, Ministerial Complex Juba, South Sudan

Appendix 10: Approval

KENYATTA NATIONAL HOSPITAL
Hospital Rd. along, Ngong Rd.
P.O. Box 20723, Nairobi.
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP", Nairobi.
Email: KNHplan@Ken.Healthnet.org
17th August 2011

Ref: KNH-ERC/ A/223

Linda Levi Chama
School of Public Health
University of Nairobi

Dear Linda

Research proposal: "Characteristics of Children with tuberculosis in Health Facilities in Juba, South Sudan" (P164/04/2011)

This is to inform you that the KNH/UON-Ethics & Research Committee has reviewed and **approved** your above revised research proposal . The approval periods are 17th August 2011 16th August 2012.

You will be required to request for a renewal of the approval if you intend to continue with the study beyond the deadline given. Clearance for export of biological specimens must also be obtained from KNH/UON-Ethics & Research Committee for each batch.

On behalf of the Committee, I wish you a fruitful research and look forward to receiving a summary of the research findings upon completion of the study.

This information will form part of the data base that will be consulted in future when processing related research study so as to minimize chances of study duplication.

Yours sincerely

PROF A N GUANTAI
SECRETARY, KNH/UON-ERC

c.c. The Deputy Director CS, KNH
The Director, School of Public Health, UON.
The HOD, Records, KNH
Supervisors: Prof. E.N. Ngugi, School of Public Health, UON
Dr. Dismas Ongore, School of Public Health, UON