

# Knowledge, Attitude and Practice, and service barriers in a tuberculosis programme in Lakes State, South Sudan: a qualitative study

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**Background:** The World Health Organisation (WHO) estimates the incidence of tuberculosis (TB) in South Sudan to be 79 per 100,000 for new sputum smear positive TB and 140 per 100,000 for all forms of TB cases. The case detection rate of 53% for all forms of TB in South Sudan is below the WHO target of 70%.

**Objective:** To explore knowledge, attitude, and practice barriers as well as service barriers to implementing TB programme in Lakes State, South Sudan.

**Method:** This was a qualitative study conducted in May 2015.

**Results:** Despite some understanding of the symptoms, causes, and consequences of TB, the stigma for TB and lack of disclosure of the disease, is very high among the local community. The limited network of TB facilities for case detection, lack of community distribution of TB drugs and lack of food at hospitals when patients were admitted for treatment, are key barriers to TB service delivery.

**Conclusion:** To overcome barriers it is recommended that the local community worldview should be incorporated into TB awareness, testing, and treatment, and attention should be paid to areas where traditional practices, such as elimination of maize, clash with modern treatments.

**Keywords:** Tuberculosis, KAP, Dinka, service barriers, stigma, South Sudan

## BACKGROUND

Globally, the World Health Organization (WHO) ranked tuberculosis as “the ninth leading cause of death worldwide”, affecting an estimated 10.4 million people in 2016<sup>[1]</sup>.

Tuberculosis (TB) is a common cause of death in South Sudan with a prevalence rate of 257 per 100,000 population<sup>[2]</sup>. The case detection rate of 53% for all forms of TB in South Sudan is below the WHO target of 70%<sup>[3]</sup>. If the disease is discovered, the treatment success rate for smear-positive tuberculosis is just 75%, which is also below the WHO target of 85%<sup>[3]</sup>. South Sudan adopted the WHO End TB Strategy in 2015 to expand TB diagnosis and treatment services in the hospitals and primary health care centres (PHCCs)<sup>[4]</sup>. As in South Sudan and other parts of Africa, systemic barriers and patients attitudes to TB treatment continue to be a hindrance in achieving TB control<sup>[5, 6, 7]</sup>. Innovative approaches maybe required to overcome some of these challenges<sup>[8]</sup>.

To work towards reducing morbidity and mortality from TB in South Sudan, BRAC, a non-governmental organization, implemented a WHO-funded “TB Reach” project in Rumbek East County and Rumbek Central County in Lakes State from July 2014 to November 2015. The population in the area is predominantly from the Dinka ethnic group, the largest ethnic group in the South Sudan, with a population of 4,500,000<sup>[9]</sup>.

This study followed a TB education programme run by BRAC from September 2014 to March 2015. BRAC’s “TB Reach” programme had significantly higher numbers of referrals and correct detection than other governmental agencies who are involved in TB work (see Table 1). However, BRAC wanted to understand if there were additional barriers that could be removed to improve education and treatment relating to TB.

## METHODS

This was a qualitative study conducted in May

**Table 1. TB Cases Referred by BRAC and other organizations at Rumbek State Hospital**

	Total number	Referred by BRAC n (%)	Referred by other organizations n (%)
<b>Number of TB sputum tested</b>	618	419 (68)	199 (32)
<b>Number of TB cases detected</b>	30	28 (93)	2 (7)

*Data from the Tuberculosis Department, Rumbek State Hospital, September 2014 to March 2015 (Unpublished data)*

2015. Fifty participants took part either in one-on-one interviews or focus group discussions (see Table 2). All the 50 participants were Dinka and were from the six stakeholder groups described in Table 2. The gender, age and education levels were diverse and not found to be significant in the analysis. Data analysis was performed on transcripts from interviews and focus group discussions. Data were categorized thematically according to content and specific categories to discover underlying factors and to perform an in-depth comparative analysis.

## FINDINGS

Many members of the Dinka ethnic community live in Lakes State. For the Dinka, healing is an interactive process, which means that illness is a community affair, and that when one is well, there is harmony and balance between people, God, ancestors, and nature. For these reasons, the Dinka do not like to be isolated for TB treatment and have significant stigmas surrounding the disease, as it affects families and one's social position (including employment and marriage practices).

There is significant stigma to TB with the Dinka. The Dinka and healthcare workers refer to it as ayiel (cholwech) or "malaria cough" in order to work around this stigma. However, this may be confusing and does not directly address the social stigma to the disease. Added to this social barrier are service barriers, making it even more difficult for TB to be detected and treated, as found in other parts of Africa [5].

This study found that respondents understood the symptoms, causes, and consequences of TB. Unfortunately, many of the community members continue to reject the disease as TB because of the negative stigma attached to it. As described further below, and in other studies [6], we found that there are knowledge, attitude and practice (KAP) barriers in the lack of understanding and accommodation of Dinka traditions, worldview, and traditional treatments and we found there are service barriers in the lack of food in hospitals, and the lack of surveillance and ability to keep and directly feed medicine to patients by community health workers.

## KAP Barriers

In Lakes State, a barrier to both detection and treatment of TB is the knowledge, attitudes, and practices (KAP) of the Dinka people. These barriers result in a lack of detection, treatment, and completion of treatment leading to low success rates [10]. Among respondents, there was some understanding of the symptoms, consequences, and treatment process of TB. However, others thought the disease was caused by worms, smoking, sour things, cow kicks, or spirits. However, in almost all cases, if respondents' family members had TB it was rejected as the disease in question. Instead, TB was referred to as ayiel (cholwech) or "malaria cough" by both patients and healthcare workers. From interview data, we believe this is because of the negative stigma attached to TB.

We learned that the Dinka people have a negative connotation with TB going back to 1972 when the German Leprosy and Tuberculosis Relief Association in Lakes State would remove TB patients for at least six months of treatment. Affected families were seen as "satan" in the words of participants, and socially excluded because of the vernacular belief that they were suffering from a curse from God. Because TB is a transmittable disease and several members of a family are often affected, the family as a whole suffered, as even those without the disease were seen as part of the "bad spirit on the specific family". In our study, participants stated that only elderly persons and patients admitted to the hospital were likely to disclose the disease to their family and community. Lack of disclosure was based on the fear of social exclusion by the community. Marriage considerations were found to be a significant factor in the non-disclosure of TB as well.

All of the 12 Dinka patients interviewed were receiving both modern and traditional treatments for the disease and included chicken and goat rituals, and the elimination of maize, sour milk, and other foods. Removal of maize from diets became a barrier to modern hospital treatment as maize was the only food offered at the hospital.

## Service Barriers

The study also found that a barrier to TB case detection

**Table 2. Respondent Groups**

	Data gathering method	Number of participants
Patient	Focus groups	12
Community Leader	Interviews	4
Community People	Focus groups	13
Traditional Healer	Interviews	4
Formal Health Care Service Provider	Interviews	2
Community Health Worker	Focus groups	15

and care in South Sudan is the limited network of TB facilities. Nationwide, only 44% of the population are within five kilometres of a health facility<sup>[11]</sup>. The county-level TB co-ordination structures are not yet functional for all 79 counties, and among the functional hospitals and primary health care centres, only 22% have TB diagnostic services and only 13% have both TB diagnostic and treatment services.

In hospital, TB and HIV are treated under the same roof because according to hospital data, 12% of TB patients were HIV positive (it should be noted that patients with HIV are heavily screened for TB)<sup>[12]</sup>. Unfortunately, this conflates the ‘curable’ (TB) with the ‘incurable’ (HIV), adding to the stigma surrounding the disease, which is a significant barrier<sup>[7]</sup>.

We also found that there has been a lack of food provided to TB patients during their hospital stay. Before 2010, patients were fed in hospital three times a day by the World Food Programme. Their breakfast consisted of porridge, while lunch was posho (maize cooked to a dough or porridge-like consistency) with milk, vegetable and nuts, while dinner was simply bread and milk. Since 2010, however, patients receive only one kilogram of maize flour. Cooking facilities are not provided and patients must supply their own attendant to prepare meals. As aforementioned, elimination of maize is a common vernacular treatment for the symptoms of TB and many respondents reported that admitted patients often left the hospital early because of this. Introduction of new approaches have been shown to be effective<sup>[8]</sup>.

Another service barrier is the fact that medicine is provided only by hospitals for patients to take home.

Community health workers do not keep medicine and there is no community based distributor of TB medication. Therefore, if there is a lack of medicine at discharge, or misunderstandings about medication, access to information and medication is limited in the community.

## CONCLUSION

We found that the BRAC “TB Reach” programme was successful in disseminating information about TB in its project areas, but a lack of government support and the lack of understanding of how the Dinka see the disease may reduce the on-going effectiveness of treatment efforts.

An important barrier to treatment is the significant dropout rate among hospital patients because of a lack of prepared food and the hospital providing only maize flour, which is often contraindicated by traditional Dinka healing practices for “malaria cough”. Further, when patients drop out and return to their communities, community health workers do not have access to medicine to continue treatment.

To overcome barriers it is recommended that the following cultural and health system issues are addressed:

- Dinka people’s worldview should be incorporated into TB awareness, testing, and treatment and attention should be paid to areas where traditional practices clash with modern treatments.
- Hospitals should provide an alternative to maize flour for TB patients.

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