KNOWLEDGE, ATTITUDE, AND PRACTICE AND SERVICE BARRIERS IN A TUBERCULOSIS PROGRAMME IN LAK ES STATE, SOUTH SUDAN: A QUALITATIVE STUDY

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IDRC Grant: 108033-002-Health Workers' Incentives in South Sudan (IMCHA)
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[1].

Tuberculosis (TB) is a common cause of death in South Sudan with a prevalence rate of 257 per 100,000 population [2]. The case detection rate of 53% for all forms of TB in South Sudan is below the WHO target of 70% [3]. 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% [3]. 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) [4]. 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 [5, 6, 7]. Innovative approaches maybe required to overcome some of these challenges [8].

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 Rumbeek East County and Rumbeek 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 [9]. 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 2015.

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
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.

Service Barriers

The study also found that a barrier to TB case detection

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

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<thead>
<tr>
<th></th>
<th>Total number</th>
<th>Referred by BRAC n (%)</th>
<th>Referred by other organizations n (%)</th>
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<tbody>
<tr>
<td>Number of TB sputum tested</td>
<td>618</td>
<td>419 (68)</td>
<td>199 (32)</td>
</tr>
<tr>
<td>Number of TB cases detected</td>
<td>30</td>
<td>28 (93)</td>
<td>2 (7)</td>
</tr>
</tbody>
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*Data from the Tuberculosis Department, Rumbek State Hospital, September 2014 to March 2015 (Unpublished data)*
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.

References

5. Woimo TT, Yimer WK, Bati T, Gesesew HA. The prevalence and factors associated for anti-tuberculosis treatment non-adherence among pulmonary tuberculosis patients in public

<table>
<thead>
<tr>
<th>Table 2. Respondent Groups</th>
<th>Data gathering method</th>
<th>Number of participants</th>
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<td>Patient</td>
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<td>Community Leader</td>
<td>Interviews</td>
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<td>Community People</td>
<td>Focus groups</td>
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<td>Traditional Healer</td>
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<td>Community Health Worker</td>
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