International Journal of Africa Nursing Sciences 1 (2014) 6–10

Contents lists available at ScienceDirect

International Journal of Africa Nursing Sciences

journal homepage: www.elsevier.com/locate/ijans

Challenges in tuberculosis care in Western Uganda: Health care worker and patient perspectives

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ARTICLE INFO

Article history:
Received 17 July 2013
Received in revised form 29 April 2014
Accepted 23 May 2014
Available online 2 June 2014

Keywords:
Health service delivery
Health worker perspectives
Patient perspectives
Tuberculosis
Uganda

ABSTRACT

Uganda is one of the high burden countries that contribute 80% of the world's tuberculosis (TB) burden. Health care worker and patient perspectives provide valuable insight into gaps between policy and practice within tuberculosis control program. This study was part of a larger mixed-methods study to explore knowledge and stigma around HIV, TB and TB/HIV co-infection. We conducted a secondary analysis of the qualitative data. Findings related to challenges faced by health care workers and patients. Patient's identified delays in diagnosis and financial burden associated with TB treatment. Health care workers called for more training on TB and TB/HIV co-infection, and identified poor referral practices between health units and lack of program funding resulting in the abandonment of DOTS programs. Training for health care workers is needed to better manage TB/HIV co-infected patients. Overall health system strengthening is needed, including referral systems tracking patients between health centers.

1. Background

In 2012, there were 8.6 million incident cases of Tuberculosis (TB) globally, and 940 000 deaths worldwide (World Health Organisation. Global tuberculosis control: WHO report, 2013). Twenty two high burden countries, mostly in Sub-Saharan Africa, contribute 80% of the world's TB burden; Uganda is amongst them with an estimated 65,000 incident cases and 4700 deaths (World Health Organisation, 2013). A major factor in the ongoing TB epidemic is the high burden of Human Immunodeficiency Virus (HIV) co-infection in Sub-Saharan Africa, which contributes to increased progression, transmission and mortality of TB (Lawn & Churchyard, 2009). TB is the most common cause of death in HIV infected individuals, and yet is largely considered separately from HIV infection (Corbett et al., 2003).

In 2012 Uganda had a TB incidence rate of 179/100,000 and 54% of TB patients were HIV positive (World Health Organisation, 2013). The TB mortality rate was 13/100,000 (in HIV negative patients), and 25/100,000 in HIV positive patients (World Health Organisation, 2013). A number of Ugandan studies revealed that TB was the leading cause of death in HIV patients, many of whom died before TB was confirmed by laboratory methods (Amuron et al., 2011; Kyeyune et al., 2010; Moore et al., 2011). Morbidity is also high: TB was ranked as the 15th and HIV the 13th highest leading age-standardized rate of disability-adjusted life years (DALYs) in Uganda relative to comparator countries in 2010 (Institute of Health Information Metrics and Information, 2013).

One of the main components of the global strategy to fight TB is the World Health Organisation's (WHO) Directly Observed Therapy, Short-course regimen (DOTS-Direct Observed Treatment Short Course). The five central tenants of DOTS are (1) political commitment with increased and sustained funding, (2) case detection through quality assured bacteriology, (3) standardized treatment with supervision and treatment support, (4) a continuous drug supply and management system and (5) a monitoring and evaluation system and impact measurement (WHO, 2011). Uganda's National TB Control Program officially follows WHO recommendations on DOTS (Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009), however the high incidence and mortality discussed above suggest that the program is not working well, likely because of chronic underfunding leading to gaps between official TB program guidelines and implementation in the districts. The TB services are integrated into the general health care system, and minimal if any additional funding is allocated to

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http://dx.doi.org/10.1016/j.ijans.2014.05.001
2214-1391/

active community involvement and ownership in the programs, which has been shown elsewhere to be key in the success of these programs (Suri, Gan, & Carpenter, 2007). TB control is an ongoing challenge for Uganda, and it is likely that the country will not reach the 2015 Millennium Development Goals (World Health Organisation, 2013).

In order to identify gaps between policy and practice, understanding challenges faced in the delivery of TB diagnosis and treatment is critical. It has long been appreciated that front line health care workers (including doctors, nurses, medical officers, community health assistants, and clinical lab technicians, amongst others) provide a critical perspective on health care delivery. In South Africa, community health care workers have helped to identify areas for improvement in TB and HIV programs, such as improvement in supervision and collaboration with other health care delivery programs (Suri et al., 2007). The patient perspective also provides valuable insight into how tuberculosis control programs work. A study of TB patients in Zambia identified a high number of health care encounters before diagnosis, high financial burden and a long travel distance as the main barriers to care; this perspective had important implications in subsequent health care reforms (Needham, Bowman, Foster, & Godfrey-Fausset, 2004). Okot-Chono *et al.* have outlined the barriers facing TB and HIV integration in Uganda; these include poor TB-HIV planning, co-ordination and leadership, inadequate provider knowledge, limited TB-HIV inter clinic referral (Okot-Chono et al., 2009). To date, no studies evaluating health care worker and patient perspectives of tuberculosis control programs have been conducted in Uganda. Local and country specific information is important to help to tailor TB programs to the cultural and behavioral context within the specific country; major variations in context exist between and within Sub-Saharan African countries. Our study aimed to explore health care worker and patient views on the major problems and challenges within the TB program in western Uganda.

2. Methods

2.1. Setting

The study was conducted in Kabarole District (population estimate 455,000 in 2010, land area 4800 km^2). The district health services consist of 47 health units with 75% of the population being less than 5 kilometres away from a health unit (Uganda Government, 2005). The district TB services follow the national TB control program (which is officially aligned with the STOP TB strategy), are organized by the District TB Officer, and are decentralized and offered through the various health units. Rural health clinics offer the standard 4 drug TB regimen (Isoniazid, Rifampin, Ethambutol, Pyrazinamide) and are supposed to directly supervise medication administration for all patients, however in reality very few patients are directly observed. Some rural clinics offer direct microscopy for diagnostic AFB smears, but few have functioning and staffed laboratories in reality. Patients who fail a first 6 month treatment, who default (discontinue their medications before completion), or who are very sick are admitted to the district referral hospital for the first 2 months of treatment and receive daily streptomycin injections in addition to the above 4 drugs. The district laboratory does have a functioning laboratory for AFB smears, cultures are not done (Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009).

For Kabarole district 2009, the cure rate (those who had a smear negative result at the end of treatment) was 15%, the treatment completion rate was 60% and the TB defaulter rate (patients that discontinue treatment before completion) was 12% (Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009). However, it is estimated that the true defaulter rate is much higher than the reported one.

2.2. Design

This study was part of a larger mixed-methods study to explore knowledge and stigma around HIV, TB and TB/HIV co-infection (Wynne, Richter, Jgangri, Rubaale, & Kipp, 2014; Wynne et al., 2012) Findings emerged as part of that study around issues surrounding the TB program and the challenges faced by health care workers and patients. This is a secondary qualitative analysis investigating those challenges.

2.3. Data gathering and analysis

Thirty two in-depth interviews were conducted. These included interviews with health care workers (4 nurses, a medical officer, a physician, and a community health assistant, n = 7), district health managers (n = 3), TB patients (n = 6), HIV patients (n = 7) and TB/HIV co-infected patients (n = 9). Health care workers were recruited using snowball sampling (initial convenience sample of health care workers suggested colleagues that might be interested in participating), and patients recruited using a convenience sample with the assistance of nurses at each clinic. With the exception of the health managers, participants were recruited from two rural clinics (primary level care) and one district referral hospital (secondary level care). The health care managers were recruited purposively from the District Regional Office. Interview guides were developed in partnership with local stakeholders, and were informed by findings from the quantitative study component of community knowledge and stigma of TB/HIV co-infection (Wynne et al., 2014; Wynne et al., 2012). Interviews were semi-structured. Interviews lasted between 15 minutes and one hour. Interviews with health care workers and health managers were conducted in English by the first author (AW). Patient interviews were conducted and recorded in the local language, Rutooro, by the 4th author (LB), and translated into English (also by LB). A second independent translation of a sub-set of transcripts was compared to ensure quality.

Transcripts were analyzed using thematic analysis to code and categorize the data. Themes were developed from these categories. A sub-sample of transcripts was re-coded by the same researcher, and a sub-set were also coded by an independent researcher to ensure credibility and confirmability (agreement in coding tree was established) to contribute to the trustworthiness of the study. Qualitative results were additionally presented and discussed with participants and key informants (a local professor that acted as a mentor, and members of the District Health Services). This member checking confirmed and validated the themes.

This study received ethical approval in Canada from the University of Alberta Human Research Ethics Board, Health Panel, and in Uganda from Makerere University School of Public Health's Internal Review Board and the Uganda National Council for Science and Technology. Participants were given a detailed explanation of the study by one of the authors (AW or LB) in English or the local language. Informed consent was given by signature or thumbprint on the consent form by each interviewee.

3. Results

Health providers and patients identified many challenges facing the TB program in Kabarole district. These range from individual level factors experienced by patients, to overarching health systems weaknesses. The main findings can be described in the following categories: Individual factors (delay in diagnosis and