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REPORTING AND INFORMATION DEFICIENCIES: A CHALLENGE FOR ASSESSMENT OF HEALTHCARE INITIATIVES IN SUDAN

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ABSTRACT

Purpose: To discuss Tuberculosis (TB) registries deficiencies in Sudan and its effect on informing policy.

Approach: A review exploring the National Tuberculosis Program (NTP) registries in 2010.

Findings: During a study to assess TB services at facility levels, NTP registries reported between 2008 and 2010 were reviewed. Although crude detection rates were available, disaggregated data by age, gender and socioeconomic status were deficient and almost reported exclusively for smear-positive TB patients. This complicated assessing the external factors that affects TB services. Treatment outcomes reflected smear-positive cases and neglected other TB categories.

Policy implications: Lack of disaggregated data cannot reflect on TB community profile, and limiting reporting to smear-positive cases could not answer questions on true prevalence rates. The NTP needs to consider different TB categories when assessing old policies and/or developing new ones.

Keywords: Tuberculosis; TB registries; information; disaggregated data.

INTRODUCTION

Health information: an important component to strengthen health systems

With the numerous emerging health challenges that the world's population is facing today, health systems are in need of structural reforms so as to conquer these challenges. This is more relevant in the developing countries,where populations still suffer from the burden of communicable diseases, combined with over-rising problems of non-communicable diseases. However, supportive information and reporting strategies are needed to achieve these system reforms. In this regard, the World Health Organization (WHO) called for strategic collection and synthesis of information covering both health systems operations and population health, and describes it as "an integral part of the leadership and governance function". Moreover, it stresses on information relevance and named it one of the health system's building blocks, where policy-makers demands of 'reliable and timely' information is a must to advise and install the proper policies. However, WHO also acknowledges that there is still much to be done to enhance the health information and surveillance systems globally (WHO,2007). This study aims to highlight the importance of high quality information and the challenges reporting deficiencies exert on health systemsin the scope of Tuberculosis (TB) services provision and evaluation.

TB global situation

TB is still considered one of the most serious and life threatening diseases worldwide and although TB mortalities has been dropping annually in this past decade, which was directly linked to the better diagnosis and treatment strategies adopted, in 2013 around 9 million individuals developed TB and 1.5 million died. This is relatively high, especially since TB deaths are considered 'preventable'. Accordingly, there was a call for immediate action to maximise efforts and ensure the achievement of global TB control targets (WHO, 2014).

TB in Sudan

TB still remains a prevalent problem in Sudan, and a major public health concern with a prevalence of 192 cases per 100,000. There are 41,000 incident cases, with 2600 of those being HIV/TB co-infected patients, and theTB mortality rate (excluding HIV/TB) reached 25 cases per 100,000, all during the year 2013. During the same year, the TB detection rate for all cases was 46%, treatment success rate for new cases registered in 2012 was 75% and for previously treated cases registered in 2012 was 64%, respectively (WHO,2014).

TB control and information management in Sudan

Although the National Tuberculosis Programme (NTP) was first established in 1970s, it remained a small part of the Khartoum Chest Hospital and of a modest managerial structure for a decade later. It was not until 1990, with the recommendations of the WHO-based on formal reviews conducted for two years, that the NTP protocol was revised. In 1993, the NTP adopted its current structure. It started to follow WHO's policy for TB diagnosis and control; Directly Observed Treatment, Short-Course (DOTS) and the International Union Against Tuberculosis and Lung Disease (IUATLD) guidelines. The NTP structure was reformed to consist of a central supervisory unit at the Federal Ministry of Health (FMOH) and several autonomous state units following the Sudanese health system's decentralised framework. The central NTP unit within the FMOH is responsible for the provision of training, intensive supervision and the provision of advanced supplies and logistics to the state units.It is also responsible for monitoring and the operationalisation of the national information system and for recommending and advocating community participation strategies. At the state level, theunits are responsible for planning, financing and delivering TB services,in coordination with other disease units and ministries directorates (El-Sony et al.,2000).

At a more operational level, each state is assigned a number of smaller management units following NTP guidelines, i.e. the TB Management Unit (TBMU). These are available in several health facilities; hospitals, health centres with selected health stations and Non-Governmental Organization (NGO) clinics. Each unit is accountable for delivering TB services to a population of 100,000–200,000 and for reporting to both state and central NTP units. Within each TBMU there is a team consisting of: a medical assistant, a laboratory technician and a clerk/statistician. The latter is responsible for delivering quarterly reports on "results of case-finding and treatment to state co-coordinators and to the central unit" according to a timely preapproved reporting plan. These reports are discussed during the state and central NTP supervisory visits and periodical meetings.The latter focuses on quality assurance, where a re-examination and interpretation of selected diagnostic sputum smears is undertaken and a standardised evaluation of the delivered result reports combined with a peer-review elaborative discussion is done (El-Sony et al., 2000).

MATERIALS AND METHODS

This review was conducted parallel to an analytical retrospective cohort, facility-based study. This full coverage research project meant to cover all pulmonary TB cases enrolled in the NTP registers in the 15 Sudanese states over a period of three years; January 2008–December 2010.It aimed to assess TB patients preferences towards the use of centralised TBMUs versus

the decartelised ones. We used the cumulative TB case detection and treatment outcome rates within each facility type as an indicator for patient's facility use. We then compared the rates of patients attending TBMUs, in Tertiary care hospitals (centralised institutions) versus those in district hospitals/PHC facilities (decentralised institutions). This was done by reviewing information routinely collected by the NTP registry from state units and available at the central NTP database. We also aimed to disaggregate those rates by different TB types and patients demographics.

The variables we looked for included:

1. number of TB detected cases – linked to TB type – in specialised hospitals (Centralised facilities) and those detected in rural hospitals/PHC facilities (Decentralised facilities) in all 15 states in 2008–2010
2. number of TB successfully treated cases, again linked to TB type – in specialised hospitals (Centralised facilities) and those treated in rural hospitals/PHC facilities (Decentralised facilities) in all three states 2006–2009 and finally
3. Some other patient characteristics; gender, age, distance between their current residence and the nearest TBMUs and socioeconomic status.

In order to collect the above, we reviewed three sets of database:

1. Quarterly and bi-annually reports extracted from the NTP registry. The information within the reports followed the standard WHO definitions for case detection, classification and treatment outcomes. Most of the reports were electronically provided in PDF format, yet some missing data was retrieved by reviewing the original patient TB cards (paper formats) used to collect patients' data.
2. Data from the facility-based survey (investment plan FMOH-UNDP2011) to categorise TBMUs facility type (weather centralised or decentralized.
3. To verify the data that we found through the NTP and to fill some gaps in the data registry, we reviewed the Health Information Directorate records for all state ministries information departments. We reorganised the data in EXCEL spreadsheets, in which they were sorted by state, centre and year and then were moved to SPSS for quantitative analysis.

RESULTS

The study team reviewed reports comprising data from all 15 Sudanese states, from January 2008 till December 2010. Data covered a total of 293 facilities, comparing 99 specialised hospitals (centralised facilities) to a total of 194 decentralised facilities

Table 1 TB cases detected (2008–2010) categorised by TB type					
Facility type	Case numbers detected and categorised by TB type				
	Smear positive	Smear negative	Extra pulmonary	Relapses	Total
Centralised	13,861	11,668	7753	1335	34,617
Decentralised	10,404	5838	4875	886	22,003
Total	24,265	17,506	12,628	2221	56,620
Source: Author.					

(102 rural hospitals and 92 PHC centres). The reports revealed that; a total 62,069 cases were detected within the study period in those health facilities. Yet, out of those 62,069 cases detected, TB type categorisation data was available for only 56,620 cases. The latter number of cases were categorised as shown in (Table 1); 24,265 cases categorised as smear positive, 17,506 cases as smear negative, 12,628 cases as extra pulmonary TB and 2221 were reported as relapses. This means that 5449 cases or 8.8% of the total cases detected originally were left un-categorized.

When reviewing treatment reports, the situation was further disrupted. According to the NTP policy at the time of the study, TB treatment outcome was only reported for the smear-positive cases, leaving other types treatment status un-reported, so we were informed to expect treatment outcomes data for the smear-positive TB patients only that is, the 24,265 cases (39.1%) of the total cases detected. However, after we reviewed the registry's database, we found treatment outcome data for only 17,095 smear-positive TB patients, this is 70.4% of total registered cases as smear-positive TB patients and 27.5% of total cases originally detected. Table 2 shows treated case outcomes by facility type.

Another interesting observation was the numbers of Defaults (A patient whose treatment was interrupted for two consecutive months or more) and Transfer-outs (A patient who has been transferred to another recording and reporting unit and whose treatment outcome is unknown) (WHO, 2011). The defaults reported were 1799. This is (10.5%) of total registered cases as smear-positive TB patients and who had available treatment outcome data in the NTP registry, and they constituted 2.8% of the total cases detected. For the Transfer-out, it was reported that − 660-(3.9% of total followed smear positive patients and 1.2% of the total detected) − were transferred to other TBMUs and their outcomes are unknown. When linked to type of facility which reported these results, it was found out that centralised facilities reports suffer more dropouts that decentralised ones.

Other individual factors: (gender, age, residence and socioeconomic status) could not be assessed due to the deficiency of data in the NTP registries. In fact, complete data about the pulmonary TB case − whether in the NTP registry or even in the TB treatment card − was rare.It is must be pointed out that the yearly TB detection reports are usually submitted at the end of the first quarter of next year and treatment outcome reports in mid of next year, and since this review took place within 2010, there was a delay in the usage of 2010 data till March 2011, and ultimately the verification, analysis and whole research process.

Table 2 Outcome for TB treated cases (2008–2010)							
Facility type	*TB case treated*						
	Cured	*Completed*	*Died*	*Failure*	*Default*	*Transfer out*	*Total*
Centralised	5660	1908	240	87	1137	425	9456
Decentralised	4921	1638	143	39	662	235	7638
Total	10,681	3546	383	126	1799	660	17,095
Source: Author.							

DISCUSSION

Recent literature supports the installation of 'effective information system' in developing countries to support TB services delivery and management, especially for the growing challenges of TB/HIV co-infections and Multi Drug Resistant TB (MDR-TB) (Fraser et al., 2007). This review did highlight the challenges a deficient information system can exert on decision-making relevant to TB diagnosis or treatment. In fact, the recent WHO report released in 2014 identified "lack of vital registration systems of sufficient coverage and quality in many countries, notably in Africa and parts of Asia" as the cause for difficulties in estimating TB mortality (WHO, 2014).

Similarly to the inaccuracy noted in this review with regard to detection rates, with almost 10% of the detected cases being uncategorised, indicates the lack of the data collected. The same WHO report mentioned above pointed out to 'uncertainty in current estimates of TB incidence'and related that to a lack of reporting plus a possible lack of diagnosis. The report called for strengthened surveillance systems worldwide, if we are to use the data available in registries to make TB relevant decisions (WHO, 2014). The WHO recommended in its report the use of a 'model surveillance', one which follows the 'a TB surveillance checklist'. This checklist was developed by an expert group upon WHO invitation and includes a list of'standards and benchmarks'a country's system must fulfill, if its data will be used for TB monitoring and planning purposes. This list not only legalises TB case reporting but gives a clear description of what is least expected of any TB reporting system (WHO taskforce, 2014). Although the Sudanesw system does follow much of the requirements on the list, it still falls short in some areas that is, provision of data on patient's data (age and gender) as was proved in this review. Accordingly, the NTP is highly encouraged to consider disaggregating the detected TB routinely, not only by TB type and state, but also by these categories (i.e. gender, age, socioeconomic status) to reflect the true community situations.

Moreover, the limited treatment follow-up reports, focusing only on TB smear-positive cases and not providing information on other TB categories (i.e. smear-negative, extra-pulmonary), fail to answer questions on the true prevalence or treatment success rates. The same goes for information on HIV/TB co-infected and MDR—TB cases. The NTP needs to consider these different TB categories, and not limit itself to the smear-positive caseswhen evaluating old policies and/or developing new ones. This again was supported in the literature, that called for special 'focus' patients follow-up from "initial diagnosis to initiation of effective treatment and then monitoring them for treatment breaks or loss to follow-up" (Fraser et al., 2007).

The smaller defaults and transfer proportions in the decentralised facilities in comparison to the centralised facilities was another interesting finding. Disaggregating treatment success rates to states shared the same conclusion indicating patients' preference for the decentralised facilities, but perhaps in a different perspective, further assessment of reporting, monitoring and evaluation functions at the level of the centralised facilities needs to be conducted, to ensure that this result is not due to a failure in reporting at the centralised level. The issues that we faced when reviewing the NTP registry information were not only draw-backs to finalising the work on this research as intended, which also led to un-expected delays within the project, but it also represented a serious challenge to the whole evaluation process. This would remain so for future assessments if these deficiencies are not addressed.

CONCLUSION AND RECOMMENDATIONS

The available TB patients data focusing on disease profile within the NTP registry were considered relatively better when compared to data availed by other disease control programs. Yet, much of data was still deficient across TB types, lacked disaggregation and did not include much of the important demographic dimensions. The latter was much-needed, not only to enhance the outcomes of the cohort study, but even on a national level, so as to adequately reflect on true TB distribution and treatment rates in Sudan. The NTP needs to revise its data collection framework and reporting strategies, so as to produce an complete information platform, essential for evaluating old policies and/or developing new ones.

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BIOGRAPHICAL NOTES

Anoud R. Omer (MBBS, MPH, MD, MSc) Community Medicine Specialist with specialised training in health policy and planning and interest in health education and research. After completing her master degree in public and tropical health, she worked for three years as the Monitoring and Evaluation Officer in Human Resources for Health (HRH) Planning directorate, Federal Ministry of Health/Sudan. In 2014, she was awarded her second master degree in Health Policy, Planning and Financing. Her interest in academia led her to start a teaching career at Al-Nealian University and to become a fellow of FAIMER-Southern African Institute (SAFRI).

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