The menace of incomplete data: a review of tuberculosis DOTS data at a tertiary hospital in southern Nigeria

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Abstract

Background: This paper presents data from a TB-DOTS centre in southern Nigeria in a bid to explore the peculiarities with incompleteness and identify weakness in data management and to proffer solutions to the problem going forward.

Methods: This was a cross-sectional records review of 146 patients seen from 2012 to 2015.

Results: The degree of data completeness reduced progressively in the course of treatment. From 73.3%, initial completeness of AAFB documentation reduced to 37.0% at the second month, and further to 14.4% at the fifth month. Mean weight gain was significant in all TB patients treated ($p<0.001$), but weight at the beginning and end of treatment course was recorded in just over a third of patients. Data on treatment outcome was not available for 83 (56.8%) of patients. Only 43 (29.5%) were recorded as cured but inference from the incomplete AFB statistics showed the numbers should be higher.

Conclusion: Significant gaps in TB data management create difficulties with TB program evaluation. Health workers at TB/DOTS sites need to be abreast with record keeping and adapt eTB manager for local use.

Healthcare data is defined as the information used to provide, manage, pay and/or report on the services used across the entire healthcare system. Data quality in healthcare is a large and ongoing problem and poor quality data still restricts the usability of data generated from patient care.[1,2] Poor quality data comes in different forms: it may be that which is not complete, fictitious or not timely reported, [3] as was the case in an outbreak of infectious disease in the UK resulting in a delay in the health authority's identification of the presence of an outbreak.[4] In some cases, it may be difficult to determine clearly if data was incomplete or the patient did not have the condition.[5]

Data management in tuberculosis (TB) control programmes has been documented to be very poor over the years.[6] This creates a gaping doubt in the conclusions reached and veracity of decisions that have been made over time using data from TB programmes.

Tuberculosis is one of the deadliest diseases in the world and currently a re-emerging disease fuelled by lots of factors including the HIV/AIDS global pandemic.[7] The global estimate of deaths from TB in 2015 was 1.8 million while that for Nigeria is stated to be 99 per 100,000 (27,000 deaths per year).[8,9] There have been remarkable programmatic strides globally to control the advancement of tuberculosis, though much effort has gone into this, including the setting up and running of national tuberculosis control programmes in most endemic countries, tuberculosis programmes are still contending with various levels and spread of drug resistant strains of tuberculosis.[10] Although all the reasons for this recalcitrance of tuberculosis may not be discussed in this publication, it is known that good programmatic decision making relies heavily on proper data management. The absence of good data could lead to confusion for the system and create difficulties with provision of true estimates of performance statistics essential for prioritising on the aspects of the health system that need strengthening. Once this is out of place, there could be significant risks to patient safety and the jobs of healthcare workers become more cumbersome. It also creates difficulty with programme monitoring and planning or forecasting.[11,12]

Poor management of data is a challenge for most of the high TB burden countries[13] and in this paper, data from a TB Directly Observed Treatment Short-course (DOTS) centre in southern Nigeria has been analysed for extent of completeness to identify peculiarities in the weakness of data management and to proffer possible solutions to the problem going forward.

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Materials and methods

This study was a cross-sectional review of records of patients seen at DOTS centre of a tertiary health facility in southern, Nigeria from January, 2012 to December, 2015 (four years). A total of 146 patients were seen during the period reviewed. The diagnosis of tuberculosis was made on the basis of positive sputum smear microscopy to detect acid fast bacilli (AFB), and/or clinical decision with radiological support as evidence of the disease.

The following data obtained from the case files and treatment cards of TB patients were analysed for level of completeness - Socio-demographic characteristics (age, sex, employment status, and educational status); site of tuberculosis (pulmonary or extra-pulmonary); patient treatment category, weight at entry and completion; bacteriological (Sputum microscopy for AFB) and radiological investigations (Chest x-ray), and HIV status. Data from the centre is usually reported to the local government tuberculosis and leprosy control programme officer who in turn reports to the state and the national programme coordinators in that order.

Data collected from patient files were entered into the spread sheet of Statistical Package for Social Sciences version 22 (IBM Corp., Armonk NY, USA) for analysis. Categorical variables were expressed as percentages and continuous variable as means ±

Table 1: Characteristics of Patients, Tuberculosis type, Treatment group and Source of Referral

Variables	Is all data available?	Male n=88	Female n=58	Total N=146
Age	Yes	84 (95.5)	54 (93.1)	137 (93.8)
	No	4 (4.5)	5 (8.6)	9 (6.2)
Employment Status	Yes	88 (100.0)	58 (100.0)	146 (100.0)
	No	0 (0.0)	0 (0.0)	0 (0.0)
Marital Status	Yes	88 (100.0)	58 (100.0)	146 (100.0)
	No	0 (0.0)	0 (0.0)	0 (0.0)
Tribe	Yes	88 (100.0)	58 (100.0)	146 (100.0)
	No	0 (0.0)	0 (0.0)	0 (0.0)
Religion	Yes	85 (96.6)	51 (87.9)	136 (93.2)
	No	3 (3.4)	7 (12.1)	10 (6.8)
Education	Yes	80 (90.9)	56 (96.6)	136 (93.1)
	No	8 (9/1)	2 (3.4)	10 (6.9)
Tuberculosis type	Yes	85 (96.6)	51 (87.9)	109 (93.2)
	No	3 (3.4)	7 (12.1)	10 (6.9)
New or retreatment group	Yes	88 (100)	58 (100)	146 (100.0)
	No	0 (0.0)	0 (0.0)	0 (0.0)
Source of referral	Yes	28 (31.8)	19 (32.8)	127 (87.0)
	No	11 (12.5)	8 (13.8)	19 (13.0)

Notes

Tuberculosis types are pulmonary (PTB) or extra-pulmonary (EPTB)

Retreatment cases: relapse, failure, and transferred-in with status unknown;

Sources of referral: Outpatient, internal medicine, paediatrics, other hospital and self

Table 2: Periodic AFB Results of Patients over the Course of Treatment

Variables	Is all data available?	Categories	Male n=88	Female n=58	Total N=146
Initial AFB	Yes	Positive	25 (28.4)	23 (39.6)	48 (32.9)
		Negative	35 (39.8)	24 (41.4)	59 (40.4)
	No	N/A	28 (31.8)	11 (19.0)	39 (26.7)
AFB at 2nd month	Yes	Positive	3 (3.4)	2 (3.5)	5 (3.4)
		Negative	31 (35.2)	18 (31.0)	49 (33.6)
	No	N/A	54 (61.4)	38 (65.5)	92 (63.0)
AFB at 5th month	Yes	Positive	0 (0.0)	0 (0.0)	0 (0.0)
		Negative	12 (13.6)	9 (15.5)	21 (14.4)
	No	N/A	76 (86.4)	49 (84.5)	125 (85.6)
AFB at completion	Yes	Positive	0 (0.0)	0 (0.0)	0 (0.0)
		Negative	7 (8.0)	6 (10.0)	13 (8.1)
	No	N/A	81 (92.0)	52 (90.0)	133 (91.9)
AFB at conversion*	Yes		22 (88.0)	21 (91.3)	43 (89.6)
	No		3 (12.0)	2 (8.7)	5 (10.4)

Notes

N/A = Not available

** Sputum conversion at second month of treatment*

SD. Level of significance was set at 0.05 for measuring associations. Level of completeness was expressed for all tables and the trend of incompleteness identified.

The socio-demographic data was complete except for that on age, religion and education; and the degree of completeness of the data ranged from 93.8% to 100%. Data on distribution of Pulmonary and Extra-pulmonary Tuberculosis among Patients was 93.7% complete. Even though the data on new or retreatment categories was complete, that on the source of referral was 13% incomplete. (Table 1)

The completeness of data from AFB testing progressively reduced from 73.3% for initial AAFB to 37.0% at the end of second month, and then further to 14.4% at the fifth month. There was more than four-fifth (80.4%) reduction in AFB data completeness from commencement of treatment to the end of the second month. The majority of TB patients, who were sputum AFB positive at the onset, had become sputum negative at 2 months of treatment; sputum conversion rate was 89.6% at the second month but 26.7% of patients did not even test for AFB on entry into the programme. (Table 2) The extent of data completeness for chest radiograph, 113 (77.7%) was higher than that for all other investigations for tuberculosis. About Three-quarters, 108 (74%) of all patients were screened for HIV. Among those screened, five (3.4%) were not counselled. There was no miss-

Table 3: Ancillary Investigations for Confirmation of Tuberculosis

Variables	Is all data available?	Male n=88	Female n=58	Total N=146
Chest Radiograph	Yes	64 (72.7)	49 (84.6)	113 (77.4)
	No	24 (27.3)	9 (15.5)	33 (22.6)
Mantoux	Yes	10 (13.4)	5 (8.6)	15 (10.3)
	No	78 (88.6)	53 (91.4)	131(89.7)
RVS	Yes	59 (67.3)	49 (84.5)	108 (74.0)
	No	29 (33.0)	9 (15.5)	38 (26.0)
Pre-test HIV Counselling	Yes	57 (64.8)	46 (79.3)	103 (70.6)
	No	2 (2.3)	3 (5.2)	5 (3.4)
	N/A	29 (32.9)	9 (15.5)	38 (26.0)
Chest X-Rays versus Sputum AFB Results				
Variables	**Categories**	**Chest radiograph frequency (%)**		
		Suggestive	Non-suggestive	N/A
Initial Sputum AFB	Positive	35 (31.8)	0 (0.0)	13 (39.4)
	Negative	44 (40.0)	2 (66.7)	13 (39.4)
	N/A	31 (28.2)	1 (33.3)	7 (21.2)

Table 4: Outcomes following tuberculosis treatment: Weight gain and others

Category	n/N	Mean weight (Completion)	Mean weight (Entry)	Mean diff.	t-test	p-value	95% *CI
Male	61/88	54.75 ±16.63	51.14 ±16.31	3.61	4.901	<0.001	5.09 - 2.14
Females	40/58	48.87 ±19.70	46.66 ±19.18	2.21	3.651	0.001	3.44 - 0.98
Mean		51.86 ± 18.36	48.82 ± 17.82	3.04	6.128	<0.001	4.02 - 2.05

Table 5: Treatment Outcomes of Patients

Is all data available?	Categories	Male n=88	Female n=58	Total N=146
Yes (43.2%)	Cured	23 (26.1)	20 (34.5)	43 (29.5)
	Failure	1 (1.1)	0 (0.0)	1 (0.7)
	Transferred-out	4 (4.5)	1 (1.7)	5 (3.4)
	Loss to follow-up	2 (2.3)	1 (1.7)	3 (2.1)
	Dead	3 (3.4)	5 (8.6)	8 (5.5)
No (56.8%)	N/A	52 (62.6)	31 (53.5)	83 (56.8)

ing data about screening for HIV among TB patients. (Table 3)

There was significant mean weight gain in all TB patients during treatment, $p<0.001$. Weight gain in males was greater than that in females. Weight at the beginning and end of treatment course was recorded in only 69.3% (61/88) of males, and 69% (40/58) of females. (Table 4)

Data on outcome was not available for 83 (56.8%) of patients. Inferring from those with documented outcome, only 43 (29.5%) were cured, death occurred in 8 (5.5%) of patients, 5 (3.4%) were transferred out, 3 (2.1%) were known to have been lost to follow-up, while treatment failure was recorded to have occurred in only one patient. (Table 5)

Discussion

The data from the TB/DOTS centre of the tertiary hospital studied shows lots of vagaries in the management of data that require prompt intervention to improve the reliability of information.

Socio-demographic data was nearly complete, and that is understandable, as it is obtained during registration into TB/DOTS treatment with a fresh and well-structured data capture tool – the TB treatment card. But a few data were still not available in the categories of age, religion, and educational status. It is likely these were not supplied as they are perceived as sensitive subjects among quite a few persons in this locale. A previous study on factors responsible for omissions in filling questionnaires had identified age and educational status as commonly omitted variables in studies.[14] On subsequent visits, if a centre has a poor filing system for instance, a treatment card used previously may not be readily accessible when data has to be entered; test result slips may get misplaced. Retrieval and proper documentation may pose a problem after this. These same views have been outlined in a publication on disadvantages of manual medical records which also highlighted loss of productivity, poor quality data, and higher cost for data handling.[15]

Since patients were categorised into Pulmonary tuberculosis (PTB) or extra-pulmonary tuberculosis (EPTB) early in the cycle of treatment, and sometimes the diagnosis of a patient poses a dilemma and drug trials even have to be done, it is likely that the few patients whose diagnosis are not captured were among those posing a difficulty with pre-treatment categorisation. A good medical record system should possess a system for preventing incomplete data sets from being stowed away.

The source of referral, though taken at the point of admission into the programme, was incomplete. It is not surprising, as the two-way referral system is not quite functional in our health system. Health workers may not have deemed it important to keep that record as they may have perceived it unnecessary due to the current mode of operation of this health system.

It may be that healthcare workers deemed it fit to keep records of only patients who came with AFB results. But since AFB is such an important test for treatment progress evaluation, and all patients are required to have done it at the stipulated times, it would have been more appropriate to also keep deliberate records of those who did not do their AFB tests instead of leaving blank spaces. With the general pattern of incomplete data, it is difficult to assume that blank spaces represent a true absence of information which is required in the first instance.

Over a quarter of patients, 26.7% were admitted into DOTS treatment without AFB results. Another two-fifths (40.4%) were negative for AFB but also admitted for treatment; meaning that clinicians have accepted that AFB false negative results are rife. Although this is the scenario at many TB-DOTS centres,16 the World Health Organization still maintains that AFB is its standard test for diagnosis of TB.[17] The Gene Xpert testing which is currently gaining ground must be given wider coverage so that TB control gains from its greater AFB accuracy.[18]

The patients who were not screened for HIV may not have consented to screening and there remains a chance that some of them are HIV positive. To prevent this, their position should have been documented as this may aid the TB/DOTS programme with decision making to adopt the opt-out approach for HIV counselling and testing.

As almost a third of TB patients did not have recorded weights for the beginning of treatment, the end, or both; the proportion of unrecorded events may have resulted in an error in the average weight gained and the conclusions reached. It is not easy to tell if there was a systematic withdrawal from treatment services. In which case, patients who were not improving were the ones who withdrew. If such a scenario is true, then the mean weight gain may not have been this large if at all it turned out significant. The TB treatment card provides cells for five periodic weight measurements. Keeping this religiously would have helped establish a trend in weight gains among patients on TB treatment. Although, previous studies have documented improvement in weight following treatment for tuberculosis, this pattern of lost data was not reported,[19,20] neither has it been seen in other free-of-charge chronic disease control programmes where there is a closer watch from managers on the data e.g. HIV/AIDS control programme. It is also not seen in the management of hypertension and diabetes for which fees are paid for services. It appears then that it is not necessarily the lack of payment for services that is responsible for poor data management in TB control programmes.[21] Rather, it is likely due to the lack of supervision and/or awareness of the importance of data integrity. Apparently, since there is no special allocation of funds for health personnel of TB programmes, the more senior health workers abandon the management of these programmes to lower cadre staff, and do not even provide conscientious supportive supervision to avoid lapses in data entry, the importance of which the lower cadre health workers may not really appreciate.

The proportion of patients who were cured, as recorded at the appropriate section of the card was 29.5%, but an analysis of table 4 which shows the AFB test results for months 0, 2, 5, and at the end suggests that the cure rate far exceeds this value. The initial proportion of patients who did the AFB was 32.9%, more patients did the test in the passing months, likely those who were added to the programme using radiological findings and clinical criteria as is commonly done in other centres especially among HIV-positive patients.[22,23] All these patients, though responding clinically to treatment, must have returned with negative AFB results as there was no record of a positive AFB result after the second month. The cumulative values in table 4 should be closer estimates of the real situation with AFB at that DOTS centre even though they would also be a shortfall due to the observed habit of poor data entry.

In the Treatments Outcomes section, Treatment Failure was recorded as an outcome for one patient. Meanwhile, the sputum AFB section showed no positive sputum AFB result at the 5th month. These data were obtained as recorded on both sides of the TB treatment card. Treatment Failure means that a TB patient who started as sputum positive did not become sputum negative throughout the period of treatment.[24] The data extracted do not identify anyone to be in that category. This mismatch suggests that the health workers in-charge of record keeping may need to be taught or refreshed on the case definitions in TB management. However, the data on HIV was complete and coherent. This may be because of the fear of HIV and health workers knew they needed to prevent anyone contracting the disease. It may also be because HIV programmes have heightened awareness on ethical issues and the need for complete data. HIV programmes also have a face to their programmes, as their organisations are well known and officers usually seen periodically reaching out for HIV data, and interact with health workers to ensure it is timely and complete for their programme performance appraisals. In tuberculosis DOTS on the other hand, the DSNO who collects data is usually neither assertive nor collaborative, and passively collects the data they are given for submission into the pool of routine data. The DSNOs need to be equipped to engage DOTS workers, find time to bring them up to date on new innovations, and they need to imbue the need for complete data into DOTS workers through occasional supportive supervision or trainings. Incomplete reporting of tuberculosis cases is not peculiar to Nigeria though, it has also been reported in the national tuberculosis control programme in the Netherlands.[25]

It has been documented that it is difficult to estimate loss-to-follow-up (LTFU) when data collection is poor, and therefore difficult to evaluate programme success and make decisions to improve programme.[26] Going forward it may be important to train and retrain health workers who manage TB/DOTS sites. Where possible, ensure each site has a health worker with tertiary education who would better appreciate the import of good data management, and make such a person responsible for data at that site.

When all the proposed have been done, there may still be the need to keep the workers continually motivated, else as humans they may begin to forget the necessary routines again. It may also be necessary to set goals and possibly incentivise good quality data which of course must also be monitored to prevent manipulation. In that case, where manipulation is noticed, there may be a need for pre-stipulated penalties.

It may already be obvious that keeping good data through health workers is quite an onerous task which the TB control programme and its funders may not be willing to take on. A way around this would be to introduce computerised systems for data integrity in TB care, including domesticating the already existing eTB Manager for local use by expanding and adapting the already existing eTB manager – an online platform for TB data management created by the Management Sciences for Health (MSH) with support from USAID – to include everyday offline use with the store and forward capabilities to enable updating of the online database once the data is exposed to the internet.[27] This database would perform maximally if constraints are placed in the logic sequence during programming to prevent the user from proceeding to a next patient if the mandatory cells in a current patient have not first been completed, especially if there is no skip logic attached to that option. The database being user-friendly would require the direct training of only a few hands per TB/DOTS site. These would in turn cascade the knowledge to their peers and colleagues. This would definitely be more effective on the long-run. Whichever method is adopted, the intended outcome of more precise data must be kept in view as its import to programme success and quality of care in disease treatment cannot be overemphasised.[6,28]

Conclusion

An analysis of four years of records of TB/DOTS data has highlighted some of the gaps in data management with regard to tuberculosis control. Significant among these were incomplete or missing data, mismatch and wrong categorisation of patient treatment outcomes. All these make evaluation as well as decision making to improve the national programme difficult. It is therefore important to train and retrain these workers who manage TB/DOTS sites on proper record keeping and to upgrade and adapt the already existing eTB manager – an online platform for TB data management created by the MSH.

Author declaration

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