

Research article

A comparison of death recording by health centres and civil registration in South Africans receiving antiretroviral treatment

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Abstract

Introduction: There is uncertainty regarding the completeness of death recording by civil registration and by health centres in South Africa. This paper aims to compare death recording by the two systems, in cohorts of South African patients receiving antiretroviral treatment (ART).

Methods: Completeness of death recording was estimated using a capture–recapture approach. Six ART programmes linked their patient record systems to the vital registration system using civil identity document (ID) numbers and provided data comparing the outcomes recorded in patient files and in the vital registration. Patients were excluded if they had missing/invalid IDs or had transferred to other ART programmes.

Results: After exclusions, 91,548 patient records were included. Of deaths recorded in patients files after 2003, 94.0% (95% CI: 93.3–94.6%) were recorded by civil registration, with completeness being significantly higher in urban areas, older adults and females. Of deaths recorded by civil registration after 2003, only 35.0% (95% CI: 34.2–35.8%) were recorded in patient files, with this proportion dropping from 60% in 2004–2005 to 30% in 2010 and subsequent years. Recording of deaths in patient files was significantly higher in children and in locations within 50 km of the health centre. When the information from the two systems was combined, an estimated 96.2% of all deaths were recorded (93.5% in children and 96.2% in adults).

Conclusions: South Africa's civil registration system has achieved a high level of completeness in the recording of mortality. However, the fraction of deaths recorded by health centres is low and information from patient records is insufficient by itself to evaluate levels and predictors of ART patient mortality. Previously documented improvements in ART mortality over time may be biased if based only on data from patient records.

Keywords: antiretroviral therapy; HIV; vital statistics registration; South Africa.

To access the supplementary material to this article please see [Supplementary Files](#) under Article Tools online.

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Introduction

Antiretroviral treatment (ART) has had a significant impact on AIDS mortality in developing countries [1–4]. However, most of what is known regarding mortality after ART initiation in developing countries derives from patient record systems in health centres and has not been validated by data from vital registration systems. Patient record systems may miss substantial numbers of deaths, leading to underestimation of mortality [5]. As clinic volumes increase, capacity to ascertain reasons for loss from care and deaths may be reduced, leading to further limitations on using patient record systems to understand mortality among individuals receiving ART.

Vital registration systems have an important role to play in the ascertainment of mortality levels generally, including that in ART patients [6–8]. However, in many developing countries vital registration is too incomplete to permit the

ascertainment of vital status with a high degree of confidence [9]. For incomplete vital registration data to be useful, it is essential that completeness of registration be reliably estimated, so that recorded death data can be appropriately adjusted when calculating mortality rates. The completeness of adult death reporting at a population level is usually estimated by death distribution methods (DDMs), which attempt to estimate the true number of deaths based on age-specific changes in population size between censuses. These methods work well, provided the assumptions hold. However, the methods may be biased due to age misreporting, migration (if not accounted for) and other factors, which can lead to estimated levels of completeness that differ substantially from true completeness levels [10,11]. Given this lack of precision, it has been suggested that alternative methods, such as capture–recapture, should be

considered in estimating the completeness of vital registration of mortality [10].

South Africa is an upper-middle-income country in which a high proportion of deaths are reported through the vital registration system. DDM-derived estimates suggest that the completeness of adult death recording increased from about 84% in the 1996–2001 period [12] to around 93% in the period after 2001 [13–15]. However, there have been few attempts to verify these estimates of completeness using alternative methodologies. In addition, DDMs do not estimate the completeness of death reporting in children. There is substantial uncertainty regarding the fraction of child deaths that have been reported, which is a major obstacle in measuring South Africa's progress towards meeting Millennium Development Goal 4.

Given the need for both better assessment of outcomes of ART programmes and better understanding of the completeness of South Africa's vital registration system, we aim to use data from cohorts of South African ART patients to determine the relative performance of the patient record and vital registration systems in identifying patient deaths.

Methods

Patients receiving ART in South Africa were identified through the International epidemiologic Databases to Evaluate AIDS Southern Africa (IeDEA-SA) collaboration, a network of ART programmes from across Southern Africa [16]. For the purpose of this analysis, patients were included only if they had recorded civil identity document (ID) numbers. Recording of patient IDs has improved over time, with over two thirds of patients having recorded IDs in recent years [6,7]. Six ART programmes contributed data: the Khayelitsha, Gugulethu and Tygerberg programmes (Western Cape province); the McCord and Hlabisa programmes (KwaZulu-Natal); and the Themba Lethu programme (Gauteng). In the early stages of their operation, all programmes attempted to contact patients who missed visits, but over time, growing patient numbers made this increasingly difficult, and only the Tygerberg and Gugulethu programmes have continued active follow-up. Participating ART programmes recorded the patient deaths of which they were aware in their patient record systems.

Civil registration of deaths occurred through the Department of Home Affairs, which maintains a National Population Register of the vital status of all individuals with IDs. At fixed times, participating ART programmes submitted a list of civil ID numbers of patients to the South African Medical Research Council (MRC), which maintains a monthly updated database of all deaths recorded in South Africa with civil IDs, obtained from the Department of Home Affairs [17]. The MRC returned to each ART programme information on the vital status of each patient, including information on the date of death and place of death if a death was recorded. Each ART programme then provided anonymized data to the IeDEA-SA data centre, including the original vital status recorded in patient files and the vital status information from the National Population Register. All IeDEA-SA programmes obtained ethical approval from local institutions before linking patient records to the MRC database and before contributing anonymized data to the collaborative analysis. In addition, the collaboration

obtained approval from the University of Cape Town Human Research Ethics Committee to receive and analyze these data.

Patients were excluded from all analyses if they had an invalid ID number or a duplicate ID (the same ID number assigned to more than one patient), or if they were recorded as having transferred to another ART programme in patient files (since ART programmes were not expected to determine the vital status of patients who were known to have transferred). For the purpose of the analysis of completeness of the civil registration system, deaths recorded by health centres were included only if they occurred between 1 January 2004 (the approximate date of the start of the public-sector ART programme in South Africa) and 365 days prior to the date on which the linkage to the National Population Register occurred (to allow sufficient time for late reporting of deaths). Similarly, for the purpose of the analysis of the completeness of death recording by health centres, deaths recorded through the civil registration system were included only if they occurred between 1 January 2004 and 365 days prior to the date on which the last patient visit/outcome was recorded. The analysis closure dates and vital registry linkage dates differed between ART programmes. Although most ART programmes linked their patient records to the National Population Register on multiple dates, this analysis is limited to the data that were available at the time that the cohorts performed their *first* linkage, due to concern that some programmes may have updated their patient files with the vital registry data after the first linkage occurred, thus compromising the independence of the two data sources.

Two multivariate logistic regression models were fitted to assess the predictors of death recording by the two systems, and the best models in both cases were chosen based on the Bayesian Information Criterion (BIC) [18]. Variables included age, sex, year, ART programme, programme location and location of death (deaths were defined as having occurred locally if the place of death recorded on the National Population Register was within 50 km of the health centre at which the patient received ART).

As in other studies of death reporting in developing countries [19–24], we used a capture-recapture approach: deaths that are identified through one recording system (the “capture” step) are matched against deaths identified through a second recording system (the “recapture” step) and the number of deaths that are identified by neither system is estimated, assuming the fractions recorded are statistically independent [25]. The capture-recapture method incorporated the covariate effects identified as relevant by BIC in the multivariate logistic regression models [26,27].

As there is a need for age- and sex-specific correction factors that can be applied to vital registration statistics, we fitted different models to predict $c(x, g)$, the fraction of deaths occurring at age x , in individuals of sex g , that are recorded through the vital registration system (further detail is provided in the Supplementary File). The best logistic model, based on the BIC, was of the form

$$c(x, g) = \frac{1}{1 + \exp\left(-\alpha - \beta g \exp\left(-2\left(\ln\left(\frac{x+1}{25+1}\right)\right)^2\right) - \gamma \ln(x+1) - \delta \exp(-x)\right)},$$

where α is a constant term, β represents the effect of male sex at young ages ($g = 0$ for females and 1 for males), γ represents the effect of age after infancy and δ represents the effect of age in infants. The predicted completeness of vital registration for the country as a whole, in 2010, was calculated by applying the resulting correction factors ($1/c(x, g)$) to the recorded numbers of deaths in South Africa in 2010 [28] and dividing the total number of recorded deaths in 2010 by the corrected total. All statistical analyses were performed using STATA version 13 (StataCorp, College Station, TX, USA).

Results

The first linkages to the National Population Register were performed in March 2008 (Khayelitsha), September 2011 (Hlabisa, McCord, Themba Lethu) and February 2015 (Gugulethu, Tygerberg). A total of 104,143 patient records were linked to the National Population Register, but 663 records could not be linked due to invalid IDs. After excluding duplicate IDs (1929) and patients who had transferred out of care (10,003), a total of 91,548 patients remained. Out of this total, 5346 individuals were recorded as dead by both health centres and vital registration, with one or both sources recording the date of death after the start of 2004. Table 1 shows the extent of the agreement between the two recorded death dates in these cases. In 79.4% of cases the two dates were within 30 days of one another, but in 4.3% of cases the two dates were more than 365 days apart. The recorded date of death was earlier on average in the vital registration system.

A total of 5207 deaths were recorded by health centres in the period between 1 January 2004 and the date 1 year prior to the date of death registry linkage. Of these, 94.0% (95% CI: 93.3–94.6%) were also recorded by the National Population Register. Recording through the vital registration system was more frequent in women, older adults and urban ART programmes (Tables 2 and 3). We could not show an effect of the province of the ART programme (after controlling for urban/rural location) or a change in completeness over time when a linear time trend was included in the model ($p = 0.14$).

A total of 13,915 deaths were recorded on the National Population Register between 1 January 2004 and the date 1 year prior to the last patient observation in each ART programme. Of these, only 35.0% (95% CI: 34.2–35.8%) were recorded in patient files, with recording in patient files being more frequent for children, individuals dying in earlier years (2004–2005) and individuals dying within 50 km of the clinic

at which they were treated (Table 2). In the multivariate analysis, differences between programmes were significant (results not shown) and the effects of age, year and location of death remained significant after controlling for other factors (Table 3).

The multivariate models in Table 3 were used to calculate the probability of a death being recorded by either of the death recording methods, for each individual, and the capture–recapture method was applied using these estimated probabilities [26,27]. Based on this approach, the estimated fraction of all deaths that are recorded through either system is 96.2%, with the proportion being marginally higher when comparing the population aged 15 and older to children under the age of 15 (96.2% vs. 93.5%).

Age and sex differences in vital registration completeness are shown in Figure 1. Differences between males and females were most pronounced in young adults (Figure 1a). Although completeness tended to decline with younger age, this trend was reversed in infants (Figure 1b). The statistical model fitted to the data estimates that the average completeness, weighted according to the age and sex profile of South African deaths in 2010, is 94.4% (87.0% in children aged <15 and 95.3% for ages 15+).

In a few cases (0.23% of 56,924 in which the patient record indicated that the patient was alive), the National Population Register suggested that the patient had died more than a year before the last recorded date of clinic attendance.

Discussion

This analysis suggests that by combining information from patient records and the vital registration system, South African ART programmes are able to identify more than 95% of deaths occurring in their programmes. This is comparable to – if not better than – levels achieved by ART programmes in high-income settings [29]. However, information from patient record systems is not sufficient by itself to obtain reliable estimates of the levels and predictors of mortality. It is particularly concerning that the proportion of deaths recorded in patient files has dropped from around 60% in the mid-2000s to around 30% in recent years. This reflects the increasing administrative pressures faced by public-sector ART programmes as they have expanded in size, and the attendant challenges in maintaining accurate records and following up on patients who miss visits. Although a number of ART programmes in developing countries have reported a trend towards lower rates of mortality over time [30–33], our findings suggest that much of the apparent mortality decline could be due to deterioration in death recording. Similarly, apparent increases over time in rates of loss to follow-up could be partially attributed to increasing rates of unrecorded mortality.

Recording of deaths in patient files was substantially higher in children than in adults, and consequently the need for vital registry linkage is less critical in children than in adults. This is probably because children have identified caregivers who can bring the child to the clinic if they are sick, and who can be contacted if the child does not return to the clinic. However, given that only a small proportion of children have recorded ID numbers, it is difficult to generalize from these findings.

Table 1. Consistency in recording of date of death

| Date of death on National Population Register | n | % |
|--|------|------|
| > 365 days prior to date of death on patient record | 189 | 3.5 |
| 31–365 days prior to date of death on patient record | 513 | 9.6 |
| 1–30 days prior to date of death on patient record | 1140 | 21.3 |
| Same as date of death on patient record | 2100 | 39.3 |
| 1–30 days after date of death on patient record | 1005 | 18.8 |
| 31–365 days after date of death on patient record | 356 | 6.7 |
| > 365 days after date of death on patient record | 43 | 0.8 |
| Total | 5346 | |

Table 2. Completeness of death reporting

| | Deaths recorded in patient files | | Deaths recorded in death register | |
|-----------------------------------|----------------------------------|------------------------------|-----------------------------------|-----------------------------|
| | <i>n</i> | % recorded in death register | <i>n</i> | % recorded in patient files |
| Year of death | | | | |
| 2004 | 98 | 90.8 (83.3–95.7) | 155 | 58.7 (50.5–66.5) |
| 2005 | 414 | 97.1 (95.0–98.5) | 681 | 60.5 (56.7–64.2) |
| 2006 | 604 | 93.5 (91.3–95.4) | 1409 | 40.5 (37.9–43.1) |
| 2007 | 874 | 92.2 (90.2–93.9) | 2572 | 32.8 (31.0–34.7) |
| 2008 | 1008 | 93.6 (91.9–95.0) | 3033 | 32.7 (31.1–34.4) |
| 2009 | 1229 | 94.1 (92.7–95.4) | 3321 | 34.2 (32.6–35.9) |
| 2010 | 799 | 94.4 (92.5–95.9) | 2297 | 29.0 (27.1–30.9) |
| 2011–2014 | 181 | 97.8 (94.4–99.4) | 447 | 34.0 (29.6–38.6) |
| Sex | | | | |
| Male | 2376 | 93.0 (91.9–94.0) | 6228 | 35.2 (34.0–36.4) |
| Female | 2831 | 94.8 (93.9–95.6) | 7687 | 34.8 (33.7–35.8) |
| Age at death | | | | |
| < 15 | 117 | 77.8 (69.2–84.9) | 133 | 67.7 (59.0–75.5) |
| 15–29 | 909 | 93.3 (91.5–94.8) | 2497 | 34.2 (32.3–36.1) |
| 30–39 | 2023 | 94.2 (93.1–95.1) | 5535 | 34.1 (32.9–35.4) |
| 40–49 | 1385 | 94.1 (92.7–95.3) | 3632 | 35.6 (34.1–37.2) |
| 50 + | 773 | 96.5 (95.0–97.7) | 2118 | 34.8 (32.8–36.9) |
| Programme locality | | | | |
| Urban | 3767 | 95.4 (94.6–96.0) | 10,423 | 34.2 (33.3–35.1) |
| Rural | 1440 | 90.3 (88.7–91.8) | 3492 | 37.3 (35.7–39.0) |
| Programme province | | | | |
| Gauteng | 2435 | 95.4 (94.5–96.2) | 8242 | 28.2 (27.3–29.2) |
| KwaZulu-Natal | 2013 | 91.8 (90.5–92.9) | 4376 | 42.5 (41.0–43.9) |
| Western Cape | 759 | 95.3 (93.5–96.7) | 1297 | 52.5 (49.7–55.3) |
| Place of death^a | | | | |
| < 50 km from clinic | – | – | 8473 | 43.1 (42.0–44.2) |
| ≥ 50 km from clinic | – | – | 5442 | 22.3 (21.2–23.4) |
| Total | 5207 | 94.0 (93.3–94.6) | 13,915 | 35.0 (34.2–35.8) |

^aPlace of death was recorded only for those deaths recorded on the death register.

Table 3. Multivariate analysis of factors associated with recording of death

| | Odds ratio (95% CI) | <i>p</i> |
|---|---------------------|----------|
| Recording of death by civil registration system | | |
| Male sex | 0.66 (0.52–0.83) | <0.001 |
| Urban location | 2.05 (1.62–2.59) | <0.001 |
| Per 10-year increase in age | 1.36 (1.23–1.50) | <0.001 |
| Recording of death by health centres^a | | |
| Age < 15 | 3.02 (2.05–4.44) | <0.001 |
| Per year of increase in date of death | 0.84 (0.82–0.86) | <0.001 |
| Place of death < 50 km from clinic | 2.32 (2.13–2.52) | <0.001 |

^aControlling for differences between cohorts.

As might be expected, recording of deaths in patient files was also substantially higher when the death occurred locally than when the place of death was more than 50 km from the health centre. This is pertinent as almost 40% of all deaths did not occur locally; South Africa's population is highly mobile, and severely ill individuals often return to their ancestral homes [34].

This analysis suggests that approximately 95% of adult deaths with IDs in South Africa are recorded through the vital registration system, which is similar to recent estimates obtained using DDMs [13–15] and a 94% completeness among individuals with IDs in a demographic surveillance site [35]. Although this consistency with DDM estimates is reassuring, this analysis raises concern about one of the central assumptions of DDMs, namely that the completeness of death reporting is constant with respect to age in adults [11]. Our results suggest that completeness tends to increase with respect to adult age, consistent with age patterns of completeness observed in Thailand [21] and the Philippines [23].

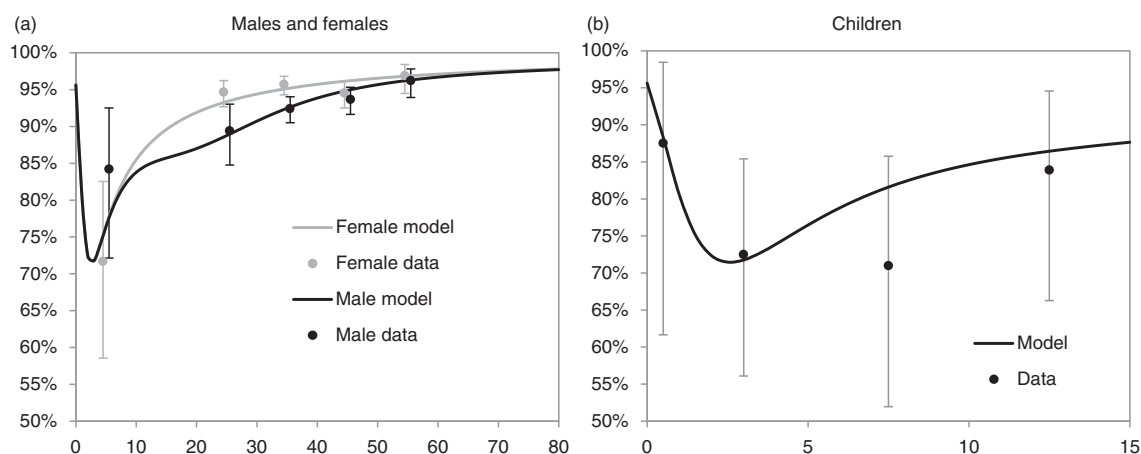


Figure 1. Fraction of deaths recorded by civil registration.

In panel (a), data plotted at ages 5, 25, 35, 45 and 55 represent the average proportions over the 0–14, 15–29, 30–39, 40–49 and 50+ age groups, respectively. In panel (b), data plotted at ages 0.5, 3.0, 7.5 and 12.5 represent the average proportions over the <1, 1–4, 5–9 and 10–14 age groups, respectively. Model estimates shown in panel (b) are the averages of the estimates for males and females. For more detail regarding the statistical model parameters, see the Supplementary File.

Simulations suggest that if the completeness of death registration is low and increases steeply in relation to age, DDMs could substantially over-estimate the true level of completeness [11]. There is thus a need for extensions to existing DDMs to correct for this bias.

Vital registration of child deaths is generally believed to be less complete than that of adult deaths [10]. Although the number of child deaths in our analysis is too small to permit firm conclusions, it is interesting to note that the results suggest a relatively high proportion of infant deaths are recorded by the vital registration system, when compared to deaths in older children. Most other capture-recapture studies have found the opposite, with death recording being relatively poor in infants and neonates [19,20,22,23], although there have been exceptions [21]. Indirect methods for estimating child mortality in South Africa have confirmed the relatively high completeness of infant death reporting by the vital registration system [14,36]. Infant deaths may be more likely to be recorded because in South Africa a high proportion of these deaths occur in health facilities, and programmes such as the Child Healthcare Problem Identification Programme have been set up specifically to improve the monitoring of these facility-based deaths [17,37].

Although this analysis suggests that the completeness of death reporting is lower in males than in females, closer investigation reveals that most of this sex differential is concentrated in the young adult ages. This may be because young men have fewer family ties, and difficulties in identifying next of kin may hinder formal notification of deaths. Deaths in young women may be more likely to be registered if they are receiving child support grants, particularly if the caregivers of their orphans wish to register for foster care grants.

Although this analysis provides important insights into the factors affecting the completeness of vital registration in South Africa, some limitations need to be considered when assessing the generalizability of these results to the country

as a whole. Patients attending public-sector services are generally of lower socioeconomic status, and HIV infection in South Africa tends to be associated with lower educational attainment and migrancy [38–40]. All of these factors might be associated with lower completeness of vital registration [35]. On the other hand, this analysis was limited to patients who had ID numbers; foreign nationals without South African IDs (who account for a substantial proportion of ART patients in some centres [41]) were excluded. Although patients with and without IDs have similar clinical and demographic characteristics [42], deaths in individuals without IDs might be less likely to get recorded by the vital registration system [35]. In addition, the ART programmes participating in this analysis were located in only three of South Africa's nine provinces, and there was a bias towards programmes in urban areas.

The finding that 35% of known deaths were recorded in patient files may not be generalizable to other settings. The programmes that are part of the leDEA-SA collaboration tend to be better-resourced than other public-sector ART programmes, with most programmes having support from academic and non-governmental organization partners. In a non-research setting, another South African study found that only 16% of deaths recorded by the National Population Register were recorded in patient files [43]. In other African countries in which tracing studies have been conducted to obtain adjusted mortality estimates, crude mortality rates range from 18 to 70% of the corrected mortality estimates [44–48]. This suggests that the fraction of deaths that are recorded in patient files differs substantially between settings, depending on factors such as the resources available for tracking patients who miss visits, the patient mix (pre-ART vs. ART-experienced) and the levels of out-migration in the population.

Although capture-recapture methods are often used to assess the completeness of mortality and morbidity recording in developing countries [49], these methods have limitations. Most importantly, the methods assume that the recording of

events in the capture and recapture steps is statistically independent; if this assumption is violated and there is strong positive dependence, the true total number of events may be substantially under-estimated (i.e. completeness over-estimated). This bias can be reduced by controlling for variables that account for the dependence [26,27], as we have done. However, to the extent that the dependence is due to unobserved covariates that cannot be controlled for, some bias is likely to remain. An alternative approach to limit bias is to collect data from a third source. In one such study from the Philippines, recording of deaths by the civil registration system was found to be strongly positively dependent on recording of deaths by health centres when compared against a third source (church records) [23]. However, it is not clear how much of the dependence would have been removed by controlling for covariates such as those considered in the present analysis.

Another capture-recapture assumption is that individuals in the two recording systems can be perfectly matched and that there are no “false-positive” records. The South African ID number is relatively unambiguous when compared to matching methods based on variables such as name, age and place of death [35]. However, there were a few cases of duplicate IDs, which might have been due to multiple patient files being opened for the same individual. There were also a few cases (0.23% of 56,924) where patient records indicated that the patient was alive but the National Population Register suggested that the patient had died more than a year before the last recorded date of clinic attendance; this could possibly be due to ID fraud (patients using the IDs of deceased individuals) or errors in the recording of ID numbers. Alternatively, these discrepancies may be due to errors in the recording of dates; Table 1 suggests that there is frequent inconsistency in the date of death recorded, and there may be similar errors in the recording of patient visit dates.

Conclusions

Despite its limitations, civil registration remains the best tool for monitoring the mortality due to HIV and other causes in many developing countries [9]. By itself, the mortality data from patient record systems cannot be regarded as sufficient for monitoring purposes, or for assessing the predictors of mortality. In countries where the coverage of vital registration remains low, efforts to improve vital registration systems should be prioritized, and in clinical monitoring systems where it is not already in place, linkage to vital registration systems should be established. Tracing of a sample of patients who are considered lost to follow-up may also yield improved estimates of mortality in situations where linkage to vital registration is not feasible [44–46].

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Competing interests

The authors declare that no competing interests exist.

Authors' contributions

LFJ, AB and MD conceived the study, while RL, RW, MPF, HP, FT and AB contributed to data collection. LFJ, RED, CJH, MC, MS, AB contributed to data analysis. and LFJ drafted the manuscript with inputs from all authors. All authors have read and approved the final manuscript.

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